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ABSTRACT

This resource book contains 43 articles to assist in addressing the problems of children with Tourette Syndrome or attention deficit hyperactivity disorder. Separate sections are provided for articles on medical, psychological, educational, and legal aspects of these conditions. Examples of topics considered in the medical section include: advances in treatment of Tourette syndrome, genetics of Tourette syndrome, diagnosis of Tourette syndrome, and the relationship between attention deficit hyperactivity disorder and Tourette syndrome. Topics in the psychological section include psychological treatment for Tourette syndrome, family problems, and the roles of various professionals. Topics in the educational section include appropriate accommodations and modifications, the roles of the school nurse and social worker, suggestions for teachers of students with Tourette syndrome, alternative placements, and vocational assessments. The legal section addresses administrative agency remedies and due process, social security benefits, law enforcement, and procedures of family courts. A final section provides brief articles on various agencies and support groups. The book also contains a glossary and a list of abbreviations. (DB)

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Attention Deficit Hyperactivity Disorder

Toughing It Out At Home and At School

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TOURETTE'S
AND
ATTENTION DEFICIT
HYPERACTIVITY DISORDER

TOUGHING IT OUT AT HOME AND AT SCHOOL

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TOURETTE'S AND ATTENTION DEFICIT HYPERACTIVITY DISORDER

TOUGHING IT OUT AT HOME AND AT SCHOOL

This resource book was developed to help both professionals and non-professionals gain an understanding of the problems encountered by persons with Tourette's Syndrome (TS) and/or Attention Deficit Hyperactivity Disorder (ADHD). Although there are no easy answers, a thorough knowledge of the symptoms and alternative possibilities for treatment can do much to alleviate the concerns of parents, friends, and others, who may be attempting to provide assistance to those affected.

An earlier book, Toughing Out Tourette's and Attention Deficit Hyperactivity Disorder, had been geared primarily for residents of Louisiana. Due to the popularity and number of requests for the book by people from all parts of the United States, the need for a new version was obvious. This edition has been streamlined and updated with new articles to better address the needs of readers nationwide.

Tourette's and Attention Deficit Hyperactivity Disorder - At Home and At School is comprised of articles written by some of the top authorities in their respective fields. The Associate Editors of the book include: Dr. Barbara Golden, M.D., a noted neurologist specializing in the treatment of Tourette's Syndrome and Attention Deficit Hyperactivity Disorder; Dr. Brenda Dawson, Ph.D., a

psychologist with the Neuromedical Center; Hank des Bordes, a well reputed Baton Rouge attorney; Denise Denicola, President of the Baton Rouge Tourette's Support Group; and John B. Kent, Jr., editor of the "TIC TALK" Newsletter and Business Manager for the Support Group. Additionally, despite the fact that Dr. Joseph Comaty, one of the most knowledgeable experts in the fields of Tourette's and ADHD, had too many professional commitments to allow him to participate fully in this project, he did serve as a consultant to insure the timeliness of some of the technical information contained in this book.

Although females, as well as males are affected by TS and ADHD, and all comments apply equally to females, because of the far greater numbers of males with these disorders as well as ease of reading, affected individuals will be referred to as "he." Additionally, as terminology for Attention Deficit Disorder (ADD) has changed within the last few years to include hyperactivity, the newer term, Attention Deficit Hyperactivity Disorder (ADHD), will be used.

The Baton Rouge Tourette's Support Group wishes to give special thanks to Attorney Hank des Bordes for giving his time to serve as legal consultant for the group, providing advice on these publications, as well as his assistance in activities advocating for the rights of the disabled.

The importance of good computer operator assistance cannot be overstated. Susan Smith, not only donated overtime for this project, but provided much needed perspective and input as to how the proposed materials might be interpreted by persons not familiar with the terminology associated with these disorders. For added assistance, words appearing in darkened print through the text have been defined in the glossary.

The Baton Rouge Tourette's Support Group also wants to express their appreciation to Elissa Murphy for the unique design of the book cover and to Dr. Richard L. Horne, Ph.D., Director of the Technical Assistance Center for Professional Development at NICHCY (The National Information Center for Children and Youth with Disabilities) for his many valuable suggestions at the onset of this project.

The Baton Rouge Tourette's Support Group is a 501(c)3 non-profit, volunteer organization which provides assistance and information through the activities of its local group, widely read newsletter, and nation-wide networking. Proceeds from the sale of this book will be used to help fund teacher attendance at workshops and conferences related to coping with student difficulties within the classroom.

Joan Murphy, M.Ed., LPC
Managing Editor

SECTION II

MEDICAL

CHAPTER

1. Advances in the Treatment of Tourette's Syndrome
Joseph Jankovic, M.D.
2. Tourette's Syndrome - What Does the Diagnosis Mean?
Barbara J. Golden, M.D.
3. The Genetics of Tourette Syndrome
David Hyman, M.D.
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5. The Relationship Between Attention Deficit Hyperactivity Disorder and Tourette's Syndrome.
John Grabert, Ph.D.
6. Finding Competent Help
Joan Murphy, LPC

1.

ADVANCES IN THE TREATMENT OF
TOURETTE'S SYNDROME

Joseph Jankovic, M.D.*

Tourette's Syndrome (TS) is now recognized as a relatively common neurological disorder. This condition is characterized by motor and vocal tics that usually begin during childhood and often are accompanied by behavioral problems, such as: Obsessive-Compulsive Disorder, lack of impulse control, and Attention Deficit Disorder.

One of the earliest reports of TS dates to 1825, when Itard described a French noblewoman with body tics, barking sounds, and uncontrollable utterances of obscenities. Sixty years later, the French neurologist and a student of Charcot, Georges de la Tourette reviewed Itard's original case and added eight more patients. He noted that all nine patients shared one feature, brief involuntary movements or tics. Since that time, many notable historic figures, including Dr. Samuel

Johnson and Wolfgang Amadeus Mozart, are thought to have been affected with this disorder.

Although the cause of Tourette's Syndrome is not yet known, nearly all patients appear to have inherited the disorder. Symptoms not only tend to vary from one individual to another, but often fluctuate within the same individual, and their expression can differ between members of the same family. Such variations can confuse diagnosis and, therefore, careful evaluation of the patient's symptoms should only be accomplished by an experienced clinician. Educational efforts directed to physicians, educators, and the general public have increased awareness about TS. In addition, public attention has been drawn to this condition by the media. As a result of this improved awareness, the self-referral rate of patients has increased and correct diagnoses are being made earlier. Unfortunately, however, many patients still remain undiagnosed or their symptoms wrongly attributed to "habits", "allergies", "hyperactivity", or "nervousness" and many other conditions.

Phenomenology of Tics

Tics are relatively brief and intermittent movements (motor tics) or sounds (vocal tics). Current criteria used in the diagnosis of Tourette's require both types of tics be present for the diagnosis of TS. This division into motor and vocal tics seems artificial, because vocal tics are actually motor tics involving the contractions of muscles which produce sounds by moving air through the nose, mouth or throat.

Simple vocal tics typically consist of sniffing, throat clearing, grunting, squeaking, screaming, coughing, blowing and sucking sounds. Complex motor tics consist of coordinated, sequenced movements resembling normal motor acts or

gestures which are inappropriately intense and timed. They may be seemingly nonpurposeful, such as head shaking or trunk bending, or they may seem purposeful, such as touching, throwing, hitting, jumping, and kicking. Additional examples of complex motor tics include gesturing "the finger" and grabbing or exposing one's genitals (copropraxia) or imitating gestures (echopraxia). Complex vocal tics include meaningful verbalizations, such as the shouting of obscenities or profanities (coprolalia), the repetition of someone else's words or phrases (echolalia), and repetition of one's own utterances, particularly the last syllable, word or phrase in a sentence (palilalia). Some TS patients also may suddenly cease all motor activity. These so called "blocking tics" may be due to tics that interrupt an ongoing activity, such as speech, or suddenly inhibit a motor activity.

Complex motor tics may be difficult to differentiate from compulsions, which frequently accompany tics, particularly in TS. A complex, repetitive movement may be considered a compulsion when it is preceded by or associated with a feeling of panic, as well as an irresistible urge to perform the movement or sound because of fear that if it is not properly executed something "bad" will happen. However, this distinction is not always possible, particularly when the patient is unable to verbalize such feelings.

Clinical Features of Tourette's Syndrome

Motor Symptoms

TS is the most common cause of tics. Because of the wide variety of motor and behavioral disturbances manifested, however, diagnosis is often difficult. To aid in the diagnosis of TS, the Tourette's Syndrome Study Group (TSSG)

formulated the following criteria for definite TS:
1. both multiple motor and one or more vocal (phonic) tics have to be present at some time during the illness, although not necessarily concurrently; 2. tics must occur many times a day, nearly every day, or intermittently throughout a period of more than one year; 3. the anatomic location, number, frequency, type, complexity, or severity of tics must change over time; 4. onset must be before age 21; 5. involuntary movements and noises cannot be explained by other medical conditions; and 6. motor and/or vocal (phonic) tics must be witnessed by a reliable examiner directly at some point during the illness or be recorded by videotape or cinematography.

Although the TSSG diagnostic criteria require that the onset is present before the age of 21, in 96% of patients the disorder is manifested by age 11. In 36 to 48% the initial symptom is eye-blinking, followed by tics involving the face and head. Vocalizations have been reported as the initial symptom in 12-37% of patients, with throat clearing being the most common. During the course of the disease, nearly all patients exhibit tics involving the face or head, two thirds have tics in the arms, and half have tics involving the trunk or legs. Tics which may include the shouting of obscenities or profanities (coprolalia), perhaps the most recognizable and certainly one of the most distressing symptom of TS, is actually present in only half of the patients. This symptom, however, is markedly influenced by cultural background. It is evident in the U.S. population (up to 60%), whereas it has been reported to occur in only 26% of Danish and 4% of Japanese patients. When describing the distress caused by his coprolalia, one of our patients remarked that immediately after shouting an obscenity, he reaches out with his hand in an attempt to "catch the word and bring it back before others can hear it." Copropraxia (obscene gestures) is present in about 20% of patients, echopraxia (imitating gestures) in 25% and

palilalia (repetition of one's own utterances) in 15%. In a study of 58 adults diagnosed with Tourette's during childhood, Goetz et al (1992) found that tics persisted in all patients, but were moderate or severe in only 24%, although 60% had moderate or severe tics during the course of the disease. Tic severity during childhood had no predictive value for the future course, but patients with mild tics during the pre-adult period had mild tics during adulthood. Poor motor control, which can lead to poor penmanship and, at times, almost illegible handwriting, may contribute to the academic difficulties faced by many patients with TS.

Behavioral Symptoms

In addition to motor and vocal tics, patients with TS often exhibit a variety of behavioral symptoms, particularly attention deficit with hyperactivity (ADHD) and Obsessive-Compulsive Disorder (OCD). It has been estimated that a majority of patients with TS have had symptoms of ADHD, OCD, or both sometime during the course of the illness. In a review of 1,500 patients with TS, 48% were diagnosed as having ADHD, a figure consistent with other studies. The symptoms of ADHD may be the initial manifestations of TS and may precede the onset of motor and vocal tics by about three years. During this time, therapy with stimulant drugs may trigger the onset of tics and may precipitate the emergence of other TS symptoms. Although attention deficit is certainly one of the most common and disabling symptoms of TS, in many patients the inability to pay attention is due to the uncontrollable intrusions of thoughts. Some patients are unable to pay attention because of a compulsive fixation or gaze. For example, while sitting in a classroom or a theater or during a conversation, their gaze suddenly becomes fixated on a particular object and despite concentrated effort, they are unable to break the fixation. As

a result of this, they miss what the teacher writes on the board or a particular action in a play. Another reason for impaired attention in some TS patients is due to mental concentration exerted in an effort to suppress some tics. It is, therefore, important to determine which mechanism or mechanisms are most likely responsible for the patient's attention deficit. This is particularly important when selecting the best therapeutic approach.

Although the fact that OCD is part of the spectrum of neurobehavioral manifestations in TS is well accepted by most, it is not accepted by all. The boundaries between normal and obsessive-compulsive behavior have not been well defined. A distinction should be made between obsessive-compulsive symptoms or traits, obsessive-compulsive personality disorder and obsessive-compulsive disorder. Obsessions are characterized by intense, intrusive thoughts, such as concerns about bodily wastes and secretions, unfounded fears, need for exactness, evenness, and neatness, excessive religious concerns, perverse sexual thoughts and intrusions of words, phrases or music. Compulsions often consist urges to repeat meaningless and irrational rituals, such as checking, counting, cleaning, washing, touching, smelling, hoarding and rearranging. Although both ADHD and OCD are regarded as integral findings of the syndrome, only OCD has been shown to be genetically linked to TS. A link between TS and OCD is also suggested by the finding in one study that 59% of 54 patients with OCD had a lifetime history of tics and 14% fulfilled the criteria for TS during the two to seven year follow up.

A common link between the motor and behavioral manifestations of TS is loss of impulse control. Indeed, most of the symptoms of TS, including some complex tics, coprolalia, copropraxia, and many behavioral problems can be explained by this mechanism. It is as if the TS patients have lost

their ability to suppress vestiges of primitive behavior. Poor impulse control might also explain the inability to control anger as a result of which many patients have frequent, and sometimes violent, temper outbursts. Some TS patients exhibit inappropriate sexual aggressiveness, and antisocial, oppositional, and even violent behavior. One of the most distressing symptoms of TS is a self-injurious behavior, reported in up to 53% of all patients. Conduct disorders and problems with discipline at home and at school are recurrent themes during discussions of behavioral problems with TS families.

Tourette's Syndrome may, in addition to tics, ADHD and OCD, express itself in a variety of behavioral manifestations, including learning and conduct disorders, and a variety of psychiatric problems. Whether these behavioral problems, indeed, occur with higher frequency in TS patients and whether they are linked to TS is debatable.

Treatment

Before deciding how to treat, it is important to decide whether to treat the TS-related symptoms. Even in our presumably more severely affected patients, about 20% do not need medication. Because of the broad range of neurologic and behavioral manifestations and varying severity, therapy of TS must be individualized and specifically tailored to the patient's needs. The most troublesome symptoms should be targeted first. The goal should not be to completely eliminate them, but to achieve a tolerable suppression. Once medications are determined to be necessary, they should be administered at the least dosage possible to be effective. Another important principle of therapy in TS is to give each medication and dosage regimen an adequate trial. This approach will avoid needless changes made as a result of

variations of symptoms as part of the natural course of the disease.

One of the most effective and least sedating tic suppressants is fluphenazine. Rarely used in treatment is haloperidol because it frequently causes troublesome sedation, depression, weight gain, and school phobia. While these side effects can also be seen with fluphenazine, they seem less frequent and less severe. If fluphenazine fails to adequately control the tics, one can switch to pimozide, molindone, or thiothixene, in that order. The most serious side effect of these drugs, other than where there might be heart or, with pimozide, liver toxicity, is tardive dyskinesia. Although this disorder rarely persists in children, a variant, tardive dystonia, found in young adults, can occasionally result in a disabling condition. Therefore, careful monitoring of the patients is absolutely essential and, whenever possible, the dosage should be reduced or even discontinued during remission or vacations. Clonazepam may also be useful, particularly in patients with severe clonic tics. Tetrabenazine is a powerful anti-tic drug that is generally well tolerated, although it may cause daytime drowsiness, nighttime insomnia, depression and Parkinsonism. This drug has a major advantage over others in that it does not cause tardive dyskinesia. Regrettably, tetrabenazine is not readily available in the United States.

Behavior modification and psychotherapy may be useful in some patients for the management of behavioral problems associated with TS, but our experience suggests these approaches are rarely effective and, at best, play an ancillary role. These behavioral strategies, however, may provide important emotional support for the patient and family members and may be helpful in raising self-esteem and improve motivation. The following classroom modifications may help the patients achieve their highest academic potential: education of teachers and classmates about TS,

allow frequent breaks and a place to "discharge" tics and emotions, shortened writing assignments, oral testing, no timed test, daily assignment list of homework, test dates, and one-on-one tutoring.

When these measures are insufficient to maintain good academic performance, the use of medications may need to be employed. We use clonidine (Catapress) in mild cases of ADHD and impulse control problems. Although mistakenly first thought to be effective in suppressing tics, this drug has been shown to be quite useful in controlling a variety of TS-related behavioral symptoms. The patch can cause local irritation, but it seems to cause fewer side effects than oral clonidine. Side effects include sedation, lightheadedness, headache, dry mouth, and insomnia.

Methylphenidate (Ritalin), although clearly effective in the treatment of ADHD, may exacerbate or precipitate tics in 25% of the patients. If the symptoms of ADHD, however, are troublesome and interfere with a patient's functioning, it is reasonable to use this or similar drugs such as pemoline (Cylert) or dextroamphetamine (Dexadrine) at the lowest dosage. Besides the possible development of tolerance, other potential side effects of these stimulant drugs include nervousness, insomnia, anorexia, and headaches. Drugs which, despite their usefulness in controlling symptoms might exacerbate tics, can be combined with others which block this effect. Imipramine, an antidepressant may also provide relief in patients with ADHD. In a pilot trial, deprenyl also seemed to be effective in controlling the symptoms of ADHD without exacerbating tics.

In patients with disabling symptoms of obsessive-compulsive disorder, the most effective drugs are imipramine, desipramine, clonazepam, fluoxetine, clomipramine, and sertraline. Clomipramine (anafranil) and fluoxetine (Prozac) are most effective (Tables 1 and 2). Fluoxetine may

also relieve symptoms of OCD. In patients with extremely severe OCD, in whom optimal pharmacologic therapy has failed, surgery may be considered as a very last resort.

It can only be speculated at this time whether certain types of drugs will exert a "protective" effect in TS. However, future therapeutic interventions should include strategies designed, not only to control symptoms, but also to alter the natural course of the disease.

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Note: "Advances in the Treatment of Tourette's Syndrome" was revised specifically for publication in Tourette's and Attention Deficit Hyperactivity Disorder, Toughing It Out At Home and At School. The original manuscript upon which this article is based was entitled "Tourette's Syndrome, Phenomenology, Pathophysiology, Genetics, Epidemiology and Treatment" (In Appel SH, eds. Current Neurology, Chicago, Mosby Year Book, 13 (1993)). For the sake of brevity and ease of reading, both the original reference citations and the bibliography have been omitted from this revised edition. Information regarding either can be found in the original publication.

TABLE 1

TREATMENT STRATEGIES IN TOURETTE'S SYNDROME

<u>TICS</u>	<u>OCD</u>	<u>ADHD</u>
Fluphenazine	Imipramine	Clonidine
Pimozide	Clomipramine	Imipramine
Haloperidol	Fluoxetine	Desipramine
Thiothixene	Sertraline	Deprenyl
Trifluoperazine	Clonazepam	Naltrexone
Molindone	Carbamazepine	Methylphenidate
Nicotine	Trazodone	Dextroamphetamine
Clonazepam		
Clonidine	Neurosurgery	
Naltrexone		
Tetrabenazine		
Sulpiride		
Tiapride		
Flunarizine		
Clozapine		
Botulinum Toxin		

TABLE 2

CLOMIPRAMINE (ANAFRANIL)

- * tricyclic antidepressant, more effective than other tricyclics and placebo in relieving OCD
- * selectively inhibits serotonin reuptake
- * dosage: 25-400 in adults; 3mg/kg in children
- * clinical effects may be delayed for several weeks
- * side effects: sedation, dry mouth, dizziness, tremor, constipation, sexual dysfunction, seizures

FLUOXETINE (PROZAC)

- * antidepressant, unrelated to the tricyclics
- * selectively inhibits serotonin reuptake
- * dosage: 20-80 mg/day
- * clinical effects may be delayed for several weeks
- * side effects: anxiety, insomnia, fatigue, tremor, sweating, anorexia, nausea, diarrhea, suicidal preoccupation (?)

TOURETTE'S SYNDROME-WHAT DOES THE DIAGNOSIS MEAN?

Barbara J. Golden, M.D.*

Tourette's syndrome is best described as a neuro-behavioral disorder with a wide variety of possible symptoms. Tourette's syndrome was first described by Gilles de la Tourette in 1885. In the one hundred years since the original description, the criteria for diagnosis, and therefore, the frequency of this disorder has varied greatly. The lifetime prevalence in the United States is now estimated at 0.5% for Tourette's syndrome and 1.6% for both Tourette's and chronic motor tic disorders. Therefore, more than one person in a hundred has a history of at least chronic motor tics.

The generally accepted criteria for the diagnosis of TS is multiple motor tics, and vocal tics, varying over a course of at least six months. The most common motor tics include eye blinking, shoulder shrugging, and facial grimacing. The most common vocal tics include coughing, snorting, and throat clearing. Complex vocal tics such as coprolalia (socially inappropriate words) occur in only a minority of TS patients (up to 1/3). Therefore, complex motor tics, vocal tics, or other behaviors, such as sniffing or spitting, are not required for the diagnosis. Most patients develop their symptoms before the age of puberty, so TS is, at the onset, a childhood disease. However, symptoms may persist, to varying degrees, into adulthood. There are other neurologic signs and symptoms which may coexist with TS. These symptoms include abnormal EEG's, soft abnormalities on the neurologic examination, and the discussed learning disabilities. TS can occur in children with mental retardation and autism - a situation that can confuse the diagnosis and complicate treatment.

It is important to emphasize that Tourette's syndrome has a continuum of severity. In and of itself, the diagnosis of Tourette's syndrome by a health professional does not determine the course of severity of that disease for any given child. All patients have a spontaneously waxing, waning, and fluctuating course, good times and bad times. Just as the diagnosis does not establish a long-term prognosis, neither does it determine the need for a specific therapy. It has been suggested that no child should receive medication for treatment of Tourette's syndrome for up to six months after the original diagnosis. This allows the family time to digest the diagnosis and read information about the syndrome. Severity of symptoms varies in 97% of patients, type and location of symptoms in 96%, and spontaneous remissions lasting one month to more than seven years are reported in 27%. Therefore, it is difficult even to predict the long term significance of the diagnosis to a given patient.

Because Tourette's syndrome is a multi-spectrum disorder, it is common for symptoms other than vocal or motor tics to be the most bothersome or potentially disabling. Among these symptoms are Attention Deficit Hyperactivity Disorder, learning disabilities, speech difficulties, behavioral problems, and obsessive-compulsive symptomatology. Each of these needs to be addressed individually for specific therapy to include medications, special education, or additional psychosocial support. Many of these aspects of Tourette's management are being further addressed in this monograph. These symptoms may actually result in a more long-term disability for the Tourette's patient unless these problems are addressed early.

What is the long-term outlook for Tourette's syndrome? As is true for many neurological syndromes, the immediate outlook is that about 30% improve, 30% worsen, and 30% remain the same. Erenberg et.al. studied the long-term outcome of patients with Tourette's syndrome and came up with

optimistic data. Most had improvement in tics with increasing age, the median age of improvement was age sixteen. Twelve percent reported that their symptoms were not interfering in their lives, 55% to only a mild degree, and 33% to a larger extent. Only five percent reported significant problems coping with their symptoms. Seventy-three percent of patients indicated that their tics had markedly decreased or almost disappeared as they entered early adulthood, and that the degree of improvement was not influenced by response to therapy or maximal severity of their condition.

Tourette's syndrome is now felt to be an inherited, genetic disorder which is autosomal dominant, but variably expressed; and with symptoms more likely to appear in males. The actual gene locus has not been identified, and the relationship to other symptoms genetically is still being hotly debated. This does have some implication for young people planning families of their own. The current genetic risk of an affected parent having an affected child, probably ranges from a high of forty percent, to a few percent.

Tourette's syndrome can and should affect the lifestyle of a young person with the disorder. Again, as is true of many neurological conditions, Tourette's patients do best when their lives are going well, and when they are at their best. Rest, illness, diet, and stress all play an important role in the person's symptoms. Medications used to treat Tourette's can have further influence with other medications or with nonprescribed drugs, such as alcohol, and illicit street drugs. A recent case report documents severe exacerbation of Tourette's symptoms with the use of Cocaine. Young people need to be aware of these risks.

In summary, Tourette's syndrome is a common, multi-faceted disorder, with a wide-range of severity. It is treatable and manageable with a good multi-modal approach to include medication,

appropriate educational adjustments, and family and patient psycho-social support. The future is bright with active research on better medications to control symptoms and increased understanding and acceptance in both the medical and lay community. The diagnosis is not one to be feared but rather to be faced and for most patients and families, there are good answers to be found.

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SYMPTOMS

TOURETTE'S SYNDROME

1. Multiple motor tics
2. Vocal tics
3. Waxing and waning over at least one year

ATTENTION DEFICIT HYPERACTIVITY DISORDER

1. Hyperactivity
2. Inattentiveness
3. Impulsivity
4. Altered response to reward, punishment (never satisfied) (motivation deficit disorder)

HALLMARKS OF ADHD

1. Inconsistency
2. A discrepancy between ability and productivity

MULTI-MODAL THERAPY

1. Medication
2. Appropriate educational interventions
3. Other, e.g. family counselling, psychotherapy, social skills training, etc.

CO-MORBID CONDITIONS

1. Obsessive-Compulsive Disorder
2. Depression
3. Anxiety disorders
4. Attention deficit disorders
5. Learning disabilities

MEDICATIONS

Generic	Brand Name
Stimulants	
Methylphenidate	Ritalin
Pemoline	Cylert
Dextroamphetamine	Dexedrine
Anti-depressants	
Imipramine	Tofranil
Fluoxetine	Prozac
Clomipramine	Anafranil
Major Tranquilizers	
Haloperidol	Haldol
Pimozide	Orap
Fluphenazine	Prolixin
Miscellaneous	
Clonidine	Catapres
Carbamazepine	Tegretol
Clonazepam	Klonopin

THE GENETICS OF TOURETTE SYNDROME

David Hyman, M.D.*

Familial aggregation of Tourette syndrome has long been recognized by doctors and their Tourette syndrome patients. Furthermore, the association of chronic motor tics and obsessive-compulsive behavior with Tourette syndrome is also increasingly clear. Whether additional disorders, including stuttering, Attention Deficit Disorder, or pervasive development delay (autism) are associated with Tourette syndrome is still highly controversial. In fact, depression, manic-depression, and even conduct disorders have been related to the presence of the Tourette syndrome gene. Not surprisingly, the controversy has generated more heat than light. Not long ago, 166 pages of data (one author of which is a past president of the American Society of Human Genetics) were published in a prestigious genetics journal stating that the frequency of Tourette syndrome, which includes any of the above features, is found in 1/100 persons. An additional 3 pages of generally negative editorial comments were generated, and then the authors of the original study responded with 8 or more pages.

In spite of the difficulty in defining the disorder, for which there are no biochemical tests, substantial progress has been made in understanding the genetics of this enigmatic disorder. The way this is being done is by studying families with Tourette syndrome who meet strict diagnostic criteria. Since at least 10% of Tourette syndrome patients have other affected family members, even using very strict criteria, considerable insight into the genetics of this disorder can be gained. For instance, such studies indicate that chronic motor tics and obsessive-compulsive behavior are signs of Tourette syndrome.

It now appears likely that many, if not most cases of Tourette syndrome are due to a genetic change at a single gene. Depending on the specific genetic change of that gene, the condition will have different manifestations. This may be one reason for the variable manifestations between different families (who may have different genetic changes in the Tourette syndrome gene). In genetic language, Tourette syndrome is presently felt to be an autosomal dominant condition with variable expression and incomplete penetrance. In an autosomal dominant gene, the condition is inherited from either a patient's mother or father. Variable expression means exactly that--some individuals with the Tourette syndrome gene may have mild manifestations, and some will have more severe manifestations. Since more men are affected than women, part of the variability seems to be sex-influenced by some, as yet unknown, mechanism. Incomplete penetrance refers to those instances where an individual must have the gene, because he or she transmitted the condition to his or her offspring, but has no signs of the condition. How frequent the gene is in the general population is anybody's guess and is a frequent point of contention between various geneticists working on Tourette syndrome.

Working under the assumption that most, if not all, familial Tourette syndrome is due to changes of a single gene, studies have been performed to determine on which of the 23 chromosomes, and on what part of the particular chromosome, the gene is located. This is called genetic mapping, and it has led to identification of the genes responsible for cystic fibrosis, hemophilia, muscular dystrophy, and a number of other conditions. As of 1991, more than half of the possible chromosome locations had been excluded as possible locations for the Tourette syndrome gene. Hopefully, by the time this is read, the exact location of the gene will be found. Then, by working backwards from the structure of the gene, scientists can determine

what function the Tourette syndrome gene performs. If we are lucky, there will be a way to correct whatever function is defective, leading, hopefully, to a specific treatment for Tourette syndrome.

The creative thinking and driving energy of scientists and physicians working with Tourette syndrome will eventually solve most of the mysteries of this condition, with the invaluable help of those who provide the financial means and the patients for successfully pursuing research. Participation of families with more than one affected member in research projects can make valuable contributions towards eventually being able to solve the genetic riddles of Tourette syndrome.

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4.

OCCUPATIONAL THERAPY
AND
THE CHILD WITH ATTENTIONAL-HYPERACTIVITY DEFICITS

Terri Todd Wilton, L.O.T.R.*

Adults or children with Tourette's Syndrome or ADD/ADHD may be referred for an occupational therapy evaluation, usually because of fine motor deficits. The referral may come from the attending physician or psychologist, the school's evaluation team, or a family friend. Adults or parents of TS or ADHD children may wonder if another test or therapy can really help.

An occupational therapist can be a valuable member in the team of professionals working with TS and ADD/ADHD children. The ultimate goal of occupational therapy is to promote independence in daily functional tasks. When assessing a child's ability, different aspects of behavior must be taken into account, such as the child's social, physical and psychological/emotional development. Also important to consider is the stage of the child's "occupation" or play/work habits. How does the child play with his toys and with his peers? How does the child perform in school, especially in regard to organizational skills and fine motor work? Can the child take care of his daily needs? How does the child contribute to the family structure? It is only through the combined efforts of the family, the child and the involved professionals that the child can be sure to function at his highest potential in daily life skills.

An occupational therapy evaluation might include any or all of the following: a parent and physician interview; a consultation with other professionals including school personnel; a gross motor, fine motor and self-care assessment; visual perception assessment; and observations of behavior (especially organizational and attentional skills), postural responses and body awareness. After identifying deficit areas, a treatment plan should be formulated with the child and parents involved, so that everyone is working toward the same goals.

Deficits often seen in children with Tourette's Syndrome and hyperactivity disorders, relative to occupational therapy, may include any of the following:

1. decreased or increased sensitivity to environmental stimuli, affecting development of body scheme
2. poor motor coordination skills, especially fine motor skills affecting self-care and school (handwriting and cutting) performance
3. visual-perceptual-motor deficits
4. poor self-esteem

A treatment plan should be designed to address the above mentioned deficits as well as any others affecting a child's functional performance. Home and school suggestions should be provided as needed to further enhance performance. Activities to improve the sensitivities in sensory systems, to enhance development of body scheme and to improve motor coordination skills are generally provided together and involve multisensory activities and timed and sequenced movement patterns. Examples of activities are as follows: touch and texture play with water, sand and other textures; art activities using pudding, fingerpaints, rice, etc.; "towelings" - using towels or paint brushes and "towelings"

different parts of the body; large movement activities (swinging); "horseplay" activities, obstacle courses that involve climbing, hopping, crawling, etc. The ideas for these type of sensorimotor activities are limitless.

A technique that has been found useful in calming down the nervous system (either to improve attention or even to go to sleep) involves the use of deep touch pressure. Examples of activities are as follows: the sandwich game - have the child lie on the floor and wrap him or herself in a blanket and then pile pillows or beanbag chairs on top; hug child tightly; and massage body parts, especially the back, using slow strokes.

Fine motor difficulties tend to go hand-in-hand with attentional and hyperactivity disorders. Specific programs can be written for mechanical deficits. Because handwriting is such an important but difficult task, assisting the school and family in making necessary adaptations is a major issue. There are numerous ideas and special equipment available that can ease the child's frustration in handwriting. Recommendations often depend on the school setting and the school's allowances. It may also be helpful to start a child with cursive writing rather than manuscript to alleviate all of the starting and stopping and thus, reducing the chances for distraction. Also, use multisensory approaches when teaching letter formations, especially using large movements, help the child learn the formations easier. Drawing and writing in other mediums, such as shaving cream, cornmeal and fingerpaint, as well as writing on vertical surfaces, are also helpful for the child.

Perceptual deficits also affect a child's functional performance. Knowing the particular area of visual perception that is delayed enables the therapist to teach compensation techniques. This might include keeping the desk free of clutter so that the child can focus on the paper, having

colored baskets in the desk to keep items organized, or using boxes to write in for spatial cueing.

Given a child with attentional and hyperactivity deficits, it is understandable how he might develop poor self-care skills and low self-esteem. Improving a child's dressing, hygiene, and feeding skills not only enables him to be more independent in the home and school setting, but most importantly, helps improve his self-esteem. Increasing the child's independence and providing him with success and positive guidance enhances his social, physical and psychological growth. From this point on, the child can grow and develop in his play and work skills.

*Terri Todd Wilton, L.O.T.R.

THE RELATIONSHIP BETWEEN ATTENTION DEFICIT
HYPERACTIVITY DISORDER AND TOURETTE'S
SYNDROME

John Grabert. Ph.D*

It has been observed that Tourette's Syndrome (TS) in children is frequently associated with a wide variety of problems including specific learning disorders, stuttering or other speech problems, obsessive-compulsive behavior, discipline problems, conduct disorders, panic attacks, phobias, and Attention Deficit Hyperactivity Disorder (ADHD). This article will help describe ADHD and examine its relation to Tourette's Syndrome.

ADHD is a condition characterized by three primary symptoms: inattention, impulsivity and hyperactivity. While estimates of its incidence range from 2% to as much as 20%, probably 3% to 4% of school-age children could be diagnosed as ADHD. It is more common in boys than girls and is more common in lower socioeconomic groups. Although ADHD is associated with multiple etiologies (causes), the most frequently noted are familial-hereditary factors and obstetrical-pregnancy complications. Toxic agents, brain damage, and temperament have also been noted as contributing to ADHD, although to a lesser degree. While poor child-rearing practices do not cause the disorder, it can serve to exacerbate the child's symptoms.

Throughout the years, researchers have questioned whether there is sufficient evidence for the existence of the disorder. The inconsistent nature of the disorder and the considerable overlap between ADHD and other disorders (e.g., learning disabilities, conduct disorders, emotional disorders, etc.) makes it difficult to assess.

Based on the most recent definition in the Diagnostic and Statistical Manual IV-R.

A. Either (1) or (2)

(1) six (or more) of the following symptoms of inattention have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

(a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities

(b) often has difficulty sustaining attention in tasks or play activities

(c) often does not seem to listen when spoken to directly

(d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)

(e) often has difficulty organizing tasks and activities

(f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)

(g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools.)

(h) is often easily distracted by extraneous stimuli

(i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of hyperactivity-impulsivity have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

- (a) often fidgets with hands or feet or squirms in seat
- (b) often leaves seat in classroom or in other situations in which remaining seated is expected
- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often "on the go" or often acts as if "driven by a motor"
- (f) often talks excessively

Impulsivity

- (g) often blurts out answers before questions have been completed
 - (h) often has difficulty awaiting turn
 - (i) often interrupts or intrudes on others (e.g., butts into conversations or games)
- B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.
- C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).
- D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

ADHD, like TS can result in behavioral, social and academic problems; the latter often involves poor productivity. ADHD exists, as does TS, along a continuum from mild to severe. With ADHD the severity of the disorder, the socioeconomic status of the family, the child's level of intelligence,

aggression, and peer acceptance can influence to some extent the child's adjustment. Tourette's Syndrome is thought to be relatively rare in children with ADHD, although, in clinic samples many children with TS are found to have ADHD. In a study comparing the two disorders several interesting findings were revealed:

The incidence of ADHD in TS was found to be dramatically higher than in the general population. Between 21% and 54% of the children with TS also have ADHD symptoms.

The incidence of ADHD for males with TS is 6 to 10 times higher; the incidence of ADHD for females with TS is 20 to 40 times higher.

The more severe the TS, the more pronounced the ADHD. For example, ADHD was seen in as many as 70% of the severe TS patients, in more than one half of the moderate TS patients, and in nearly one third with mild TS.

Stimulant drugs are probably the most common treatment for ADHD children. They are highly effective in the short-term management of attention span and impulse control. This can result in the improvement of play behavior, social interaction, and, ability to comply with directions and rules. The use of stimulant medication, however, results in little improvement in academic achievement.

Although stimulant medication can produce dramatic improvements in the behavior of the ADHD child, drug treatment remains controversial. It is not without problems and precautions. For example, there are no accepted criteria for deciding which patients with ADHD should be treated with stimulant medication. Some professionals believe that occasionally stimulant medication can precipitate TS in patients who did not previously manifest symptoms of this disorder. Others believe that stimulants can occasionally exacerbate tics but do not cause TS. In fact, stimulants are believed to

be a valuable adjunct to the treatment of TS. If the ADHD child has a family history of tics, a stimulant medication trial is approached cautiously.

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6.

FINDING COMPETENT HELP

Joan Murphy, LPC*

By the time a diagnosis of Tourette's Syndrome or Attention Deficit Hyperactivity Disorder is made, many individuals have already experienced major social, behavioral, and educational difficulties due to the presence of the more subtle symptoms. They are likely to have alienated others with their moodiness, inconsistency, irresponsibility, immaturity and inability to think before acting. Most will have known many failures and few successes. Although the earlier these individuals can be identified, the less pronounced the damage will usually be, a considerable number of nonmedical professional services may also be required. Finding competent help, whether through private or public resources, is generally the same and just requires following some basic guidelines.

Good referrals can come from a variety of sources: doctors, teachers, friends, relatives, and local or national members of support groups. Affiliation with a local Tourette syndrome and/or Attention Deficit group can be advantageous in many ways. Aside from the general and informational activities conducted by these groups, members are usually aware of current government programs and policies, which could include: financial assistance, testing services, employment, training, and educational programs for those affected. Much can also be learned from others who have faced similar obstacles. Suggestions by group members not only can simplify finding competent help, but provide short cuts through the bureaucratic red tape often encountered.

Those persons who acquire the habit of keeping written records may avoid wasting much time and energy. Many more answers can be obtained when

questions are written-out and organized prior to private conversations or meetings. In general, information and advice will tend to be more reliable when the other person is aware that a written account is being made. Time spent in recording the data: agency contacted, name of person with whom one is speaking, and the gist of the conversation can prove very worthwhile for future reference.

Although finding specialists familiar with Tourette's and attentional disorders is desirable, it is not always possible. Many professionals, despite proficiencies in their respective fields, may be unfamiliar with the symptoms. This should not necessarily preclude their services. Relevant information about either or both conditions, as well as the names of reliable local resource persons, might easily remedy the problem.

An individual should feel at ease speaking with the service provider. As a rule, sufficient time should be allocated during meetings to describe problems encountered, identify possible goals, have questions answered, and voice concerns. Responses need to make sense. If a person requests clarification or information, the specialist should attempt to give it without appearing to be condescending. All are well advised to be leery of those who too strongly agree or disagree with everything said, promise results which sound too good to be true, or claim successes where others have failed. No specialist should profess to know exactly how a patient feels, nor attempt to assume responsibility for making decisions in his best interests. Very careful consideration must be given anything requiring a signature, for despite any verbal assurances, only what appears in print is likely to be honored. People need be especially suspicious when not afforded ample time to fully consider any commitments.

Parents might have a particularly difficult time locating assistance which will be appropriate for their children. They may find remaining objective and making any decisions about their children very stressful. Those who might feel uncomfortable in such situations should ask a trusted friend or relative, familiar with the family, to accompany them. Persons chosen should be capable of remaining uninvolved, yet able to ask questions on behalf of the child and his parents.

A fairly accurate assessment as to the effectiveness of the assistance provided can often be obtained by merely asking the child. Sometimes, however, especially when attempting to change behaviors, children may rebel and things could become worse before improving. In these instances, however, parents should be forewarned as to how their child might respond. Whatever is suggested should be logical. As children differ, a particular treatment which might have worked extremely well for one child, even if successful, will probably not have the same effect upon another. Progress towards the attainment of desired outcomes may be slow or sporadic. Parental expectations must be realistic. To as great an extent as possible, the child should take an active role in all decisions. His involvement in defining difficulties, finding viable options, and evaluating results, in itself, can be highly therapeutic.

As personal preferences do differ, even the most competent specialists cannot be expected to relate equally to all people. No definite rules can be given as to when a change should be considered. Adults who find themselves disliking the specialist at their first meeting or frustrated by a lack of results would be well advised to find another. Parents considering making a change involving their ADHD children should let them know well in advance. As these children have a particularly difficult time adjusting to new

situations, parents considering having their child see someone new or having him switched into what might be, perhaps, a better program may discover such a change not worth the possible repercussions.

A diagnosis of Tourette's Syndrome and/or Attention Deficit Hyperactivity Disorder may do much to explain why an individual may have encountered many kinds of problems. The services of some specialists, such as psychiatrists, psychologists, counselors, occupational and speech therapists and educators may be needed to remediate long standing difficulties. The task of locating competent professionals and ensuring appropriate services can be greatly simplified by having a few key contacts, obtaining referrals from reliable sources, and employing common sense guidelines.

*Joan Murphy, LPC

SECTION III
PSYCHOLOGICAL

CHAPTER

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9. Tourette's: A Family Challenge
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 Floyd Heurtin, Jr., BCSW, ACSW
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12. The Private Practice Sector
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- II. The Role of the Private Clinical
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- III. The Role of the Private Clinical
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 Joseph G. Delatte, Jr., BCSW,
 Ph.D.

PSYCHOLOGICAL TREATMENT FOR TOURETTE'S SYNDROME

Brenda Dawson, Ph.D.*

Often when people hear their physician say that she or he is going to refer them to a psychologist, they have a negative reaction because they think that it means that "it's all in their heads," or that their physical problem is caused by deep, underlying psychological problems. That is not necessarily the case, and hopefully, this chapter will help one understand the value of psychological interventions in the comprehensive treatment of many physical problems, including Tourette's Syndrome.

The primary misconception usually made is that seeking the services of a psychologist is equal to admitting that the problem is non-organic. One must keep in mind that for many of these disorders there are imperfect or undesirable medical treatments. All people do not find drugs effective in the treatment of some organic problems for example, Attention Deficit Hyperactivity Disorder, Chronic Pain Disorder, and Enuresis. Additionally, some of these drugs have undesirable side effects, and the physician may prefer to use them only as a last resort. People are complex, and it is not uncommon for people who develop physical problems to find they are also faced with accompanying behavioral and social difficulties. Psychological treatments can be very helpful in coping with such problems.

Psychological treatments can be particularly effective in two main ways. First, they can be used to reduce the occurrence of the problem behaviors. Secondly, they can be used to help the individual cope with the disorder, so that he can live a more satisfying and productive life. Also, in the case of children, psychologists can help

parents deal with their child's difficulty constructively.

Before psychological treatments are instituted, a thorough physical examination as well as a psychological evaluation should be undertaken to determine if there are other areas of difficulty which might complicate treatment. For example, a child referred for motor tics and some oppositional behaviors might be found to be functioning in the intellectually gifted range. A regular classroom might create undue stress from his remaining bored and unchallenged. Switching the students to a more appropriate class might reduce the tics, because of stress reduction.

A good baseline of the behavior one wants to change, such as the tics, should be obtained for a few days. This must be done in order to evaluate whether change, however small, has occurred. This is especially important with many behaviors which change at a moderate pace, for example, a 20% decrease in the occurrence of tics might not be apparent to the observer, unless the behavior were charted before and after treatment.

Once the physical and psychological evaluations have been conducted and a baseline of the behavior established, treatment can begin. There are a number of possible interventions for reducing undesirable behaviors. The following behavioral techniques have been found to be effective in reducing tic behaviors: self-monitoring, contingency management, relaxation training, stress management, and habit reversal.

Self-monitoring. This refers to keeping a written log of each time the behavior occurs. Not only does it allow the individual to be more objective in seeing whether or not a medication or behavioral treatment is working, but a number of studies have shown that the mere act of writing down a behavior, often leads to an initial

reduction in it. Young children often have difficulty with this and require help from their parents.

Contingency management. This is any environmental manipulation that leads to a change in the behavior. In the case of illnesses, it is used mostly to help children stick to their treatment or to keep them from using their illness to avoid undesirable activities, such as school or doing chores. The child and the parent must agree upon a contract that spells out exactly what the child needs to do to earn points towards a reward (contingency). The parent should be certain the reward is something the child truly wants and be willing to be flexible in renegotiating a contract. The contract should be set up so that the child is sure to succeed in the beginning...just slightly challenging. After he has mastered the initial tasks, increasingly more difficult contracts can be arranged. In clinical practice the greatest problems arise when the parents do not follow through on the reward or believe that the child's improved behavior merely shows he could do it on his own and shouldn't have to be "bribed". This really is not fair, as changing behaviors often can be a difficult and arduous process. Providing an "incentive" simply recognizes that the changes had involved hard work. The fact that it works, in no way proves that the problem is not physical or that it is being done voluntarily. Rewards often help people become more aware of the problematic behaviors, so that they can do something to try to stop them.

When children use their disorder to get out of work, it is best to be firm but kind, and ignore the excessive complaining. It is more productive, instead, for one to express the expectation that the child will be able to do the work. Once one gives in to a child's demands, it is harder to say no in the future, something which children know all too well!

There are several studies which have shown that effective contingency management and other types of behavior management techniques can lead to physical changes in the brain, analogous to those seen with effective medication. That is while physical changes can lead to psychological benefits, the opposite appears to be true as well: psychological changes can lead to physical benefits.

Relaxation training. Most children acknowledge that their tics become worse when they are anxious or under a lot of stress. Learning to relax is a very desirable skill to have on hand in all sorts of situations. It is not as easy as it sounds, and, in most cases, requires formal training. It has been hypothesized that relaxation can directly affect the body's chemicals which alter its physiological functioning. There are a number of relaxation techniques but most involve learning how to relax properly tense muscles in a systematic fashion. Although children can learn these techniques alone, they benefit more when a supportive adult can guide them through the steps. It is recommended, therefore, that when a therapist teaches these relaxation techniques to a young child, one of the parents be present to help the child use them at home.

Stress management. This includes relaxation training but also involves identifying those situations which trigger frustration and other emotions in the child. Once the stressful situations have been identified, ways are determined which might either reduce or eliminate contact with these situations, or to teach the child how to cope with the stress by changing his attitude. Poor academic grades, a bully who is teasing the child, and parents who are not getting along are just a few examples of stressful situations many a child must face.

Habit reversal (Competing response training).

This is the most common procedure used to help people gain control over tics. In using this procedure, the person practices movements which are incompatible with the involuntary movement (tic). This might involve stretching the neck in the opposite direction to avoid a motor tic, swallowing, coughing, or clearing one's throat, instead of emitting a vocal tic, or sitting on one's hands to avoid a hair-pulling compulsion. Some people try these on their own, but do not use them systematically along with a **self-monitoring** and contingency management, hence they fail.

Many interventions have been found useful in helping people cope with tics, as opposed to, per se, reducing the frequency of the tics. Indirectly, however, these coping interventions can have the added benefit of lessening the frequency of the tics. This is especially true when the tics are made worse by stress and negative emotions such as tension, fear, and anger.

Assertiveness training. Of utmost importance is that the adult or child is able to explain his disorder to others. (Perhaps, it would be unnecessary if people always minded their manners.) Often the child is teased because the other children do not understand the tic is a medical problem that is hard to control. They may avoid the child because they are frightened by his tics. Most children with tics can get along with other children quite well once they can explain their disorder in a matter-of-fact way and can shift the focus away from the tics. Teachers and parents can also help.

Supportive therapy. Supportive therapy can be especially helpful if there are other stressors in the child or parents' lives. It can be of assistance in helping individuals locate resources, activate these resources, maintain a positive attitude, and strengthen their resolve that "no

matter what the future holds", they will be able to cope with it. At times, tics may be more stressful for the parent than the child, especially when the tics change the physical appearance of the child, and supportive therapy may be very important for the parents. This type of therapy can also be especially helpful if the child is experiencing stress due to specific problems, e.g. poor grades, a death in the family, parental divorce, etc.

Environmental stress reduction. If the child is in a situation which increases stress, changing the situation alone may decrease the number of tics. For example, it may be possible to change the child's living situation, to keep a child away from certain other children, or to make changes in the child's school environment in order to lessen the pressure on him.

When Tourette's Occurs With Other Problems

When then tics are accompanied by other disorders and/or there are many stressors in the family, it may be difficult for parents to bring into effect the behavioral techniques previously discussed, to reduce the tics. If this is the case, family therapy should be conducted in order to allow these techniques to be used more effectively. When Tourette's occurs with other disorders, such as Attention Deficit Hyperactivity Disorder or an anxiety disorder, treatment is more complicated, and the psychologist must determine which problem to deal with first. This decision will be based on a number of factors, including consideration as to which problem has the highest probability of successful reduction, and the one which might be causing the greatest difficulty in daily living. A psychologist will also try to determine the problem, which if dealt with at the onset, might lead to a change in other problems without direct intervention. Having another problem change without direct intervention, as a result of changing another behavior is referred to

as response generalization or behavior change for free.

Our society is not oriented toward preventive psychological care, although most will acknowledge its importance. Especially with regard to Tourette's Syndrome and Attention Deficit Hyperactivity Disorder, "An ounce of prevention is worth a pound of cure." If after a few sessions of psychotherapy, parents can learn about the types of problems they will face and how they might better cope with such difficulties, the child is able to deal with his peers and others with regard to their reaction to his disorder and acquire means to avoid problematic behaviors, then each of the techniques described are more likely to be effective. Additionally, if preventative care is instituted at the time of diagnosis, more intensive treatment can be avoided later.

Tourette's Syndrome is but one example of the many physical disorders that can be helped substantially through psychological methods. These psychological methods are an important part of a comprehensive treatment which has the added benefit of empowering a patient and allowing him to feel he has some control over his disorder.

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8.

COPING WITH SOCIETAL REACTIONS TO
TOURETTE'S SYNDROME

Gary G. Gintner, Ph.D.*

One of the most difficult things about coping with Tourette syndrome (TS) is not so much the symptoms themselves, but their social consequences. Why do others have difficulty relating to an individual with TS? What can be done to reduce strained interactions?

The purpose of this article is to address these two questions and offer some concrete suggestions about improving the quality of interpersonal interactions.

Contributors to Strained Interactions

To understand why social interaction can be difficult, both sides of the interpersonal exchange must be addressed. In a very real sense, each side's "reaction" influences the other's response. Peers and coworkers when encountering an individual with TS may find the behaviors unfamiliar and perplexing. The social psychological literature indicates that under these conditions the novel or unusual behavior may prompt a disruption of smooth

social relations. Consequently, an explanation is sought to reduce uncertainty. In the case of TS, others may attribute the behavior to a "mental problem" or simply poor discipline. As a result, negative or avoidant reactions may ensue.

How the individual with TS responds to these reactions can either facilitate or inhibit further interpersonal contact. As others, the TS individual can cope with an uncomfortable situation by avoiding it. Research has shown that the degree of teasing and negative interaction in school predicts the degree of social isolation and school refusal in children with TS. A second type of reaction may be to say or do something aggressive. Tourette's aside, aggressive behavior typically results in poor quality interaction in the future. While social isolation and aggressive responses may deal with the discomfort in the short-run, both carry "double interest rates" in the long-run. First, neither undoes the basic misunderstanding about the syndrome itself. Second, the lack of sustained interactions with others may inhibit the TS individual's development of age-appropriate social skills. Interestingly, TS individuals with good quality social skills can do quite well socially and on the job.

Suggestions for Improving Social Interactions

Increasing contact and providing information are two strategies that have been investigated relative to improving social acceptance. Findings indicate that neither incidental contact nor education, independently, do much to foster acceptance. However, the combination of sustained contact and education has been shown to be quite effective. Practically, this suggests that it behooves an individual with TS to not only engage in social contacts, but also to provide an explanation to others about their syndrome. A good first step would be to rehearse giving this explanation to a family member. The family member

can then provide feedback about improving the response (e.g., "Your words were great, but you didn't maintain eye contact"). Another aspect of this explanation may include the particular nature of the symptoms: "Sometimes if I get excited or nervous, they get worse, but if I it sometimes helps."

There are a number of things an individual with TS can do to make interpersonal interactions more comfortable and productive. Remembering that the initial responses of others may simply be artifacts of encountering the unfamiliar may help to take these reactions less personally. Cognitively, it is important to tell oneself: "Take one step at a time. Keep yourself relaxed. What is it that I want to say?" If there's a bit of internal tension, it is useful to pause and just get one's breathing even (i.e., time of inhales=time of exhales). These simple steps can help reduce anxiety which may exacerbate symptoms or fuel avoidance behavior. When talking with others, it's useful to maintain eye contact and try to be sure talking time is about equal. The latter can be promoted by asking questions that do not have a one-word answer ("Tell me about some of the things you do for fun.") Again, rehearsing with another may help make these types of responses more natural.

In the final analysis, sustained, good quality interpersonal interactions, as well as a straight forward explanation, may be one of the best antidotes against societal misunderstanding.

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TOURETTE'S: A FAMILY CHALLENGE

Floyd Heurtin, Jr., B.C.S.W., A.C.S.W*

The purpose of this entry is two fold. The first is to explain the emotional impact that a diagnosis of Tourette's syndrome can have upon a family. The second is to offer some insights and suggestions that will assist the family in adjusting to and coping with this diagnosis.

The initial emotional reaction to a diagnosis of Tourette's syndrome is often one of confusion, anger, denial, guilt, fear, embarrassment or shame, and sometimes even relief. It is important for the family to recognize that all of these emotions are very normal, natural reactions to something that is very, understandably, upsetting. It is also important for the family to recognize that a unique type of grieving process has been initiated. To be sure, something has been lost. It may be the image of the ideal child, or the parent's desire to live a bit more independently of that child. Conversely, the child may feel that he has lost the ability to live a bit more independently of his parents. Each family member should reflect and identify what he or she has lost. Once this is done, it should be discussed with other family members, along with an open sharing of feelings.

What is unique about this particular grieving process is that the loss is not a permanent one. Although there may be some lost hopes and dreams, the challenge to the family is not only to accept and identify the loss, but to also continue to function and grow despite being reminded of that loss on a daily basis.

Meeting this challenge can often be a very difficult and frustrating task. It is, by no means, however, an impossible one. The key elements necessary to meet this challenge are communication, creativity, education, and a sense of humor.

Communication at this point in time is critical. Family members need to discuss their feelings, thoughts, hopes and fears openly. There is as much need for listening as there is for talking. It should also be recognized that no two people are ever at the same place, in the grieving process, at any given time. Understanding the feelings of another family member, even though one may not feel that way is important.

Creativity is another key element. The family will be faced with problems and situations that have not been encountered before. While it is important to remember that some serious problems have been successfully dealt with in the past, it is equally important to recognize that old solutions generally do not solve new problems.

Education is another key element necessary to meet this challenge. Reading whatever materials are available is important. Attending a support group is also vital. Each of these activities can provide new information and allow the family to be creative in developing solutions to problems which will have to be faced.

Finally, a sense of humor is a necessary element in helping the family to meet this challenge. It has often been said that laughter is the best medicine. Laughter stimulates the flow of blood and oxygen to the brain and rest of the body, which allows an individual to think clearer and function better. It also causes the release of chemicals, called endorphins, by the body which elicit feelings of well being and relaxation.

In summary, it can be said that a diagnosis of Tourette's syndrome is one that will have a serious emotional impact on the family. It can also be said that it can be potentially harmful to the family's sense of unity and its ability to function and grow. If family members, however, employ the elements of communication, creativity, education, and a sense of humor, each can develop new strengths, coping abilities, and a heightened sense of self-esteem.

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MEETING THE NEEDS OF ALL FAMILY MEMBERS

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The impact of a diagnosis of Tourette's syndrome on a family was discussed in the previous article. It was asserted that the other family members, as well as the identified patient, are asked to cope with a unique type of grieving process. Some of the expected emotional reactions accompanying that process were also identified, as well as suggestions provided for coping with it.

The purpose of this article, will be to identify the final phase of the grieving process and discuss the family dynamics that can sometimes inhibit individual members from successfully resolving their own feelings of loss. Before all of this is understood, some concepts will need definition and explanation. These concepts are reinvestment, honesty and assertiveness, boundaries, and enabling. Finally, an attempt will also be made to demonstrate how family members who have completed this final phase of the grieving process and understand their own family's unique dynamics are actually in a better position to provide care for another family member diagnosed with Tourette's or any other chronic illness.

Worden (1982) has identified reinvestment as the final phase of the grieving process. He defines this phase as one in which the individual, who has sustained the loss, has accepted its reality and has placed his time and energy into either a new, or a different area of his life. This is a difficult task for family members to achieve, because of the constant reminders of the loss. However, it must be remembered that reinvestment requires accepting the reality of the loss, as well as placing one's time and energy into other activities. These activities are a matter of

personal choice, and can range from things that are Tourette's related, to things that are done alone. The two key terms here are acceptance and personal choice. While it is necessary to accept the reality of the diagnosis and the changes it forces on one's life, it is also necessary to acknowledge and meet one's own needs.

The concepts of honesty and assertiveness must also be understood. Family members should strive to be honest both with themselves and the others about their thoughts, feelings, and needs. Although honesty is sometimes painful, it will enhance family functioning if it is used regularly and supported by others. Assertiveness is also crucial. Each family member must learn to express those deeply held feelings and pursue their own needs. In a family that functions well together, each supports one another's assertive efforts to express feelings, and meet needs.

Another key concept is that of boundaries. Kerr and Bowen have asserted that all families are characterized by an emotional system. They further maintain, that this system is held together by a tension between two needs that all people have - individuality and togetherness. Although all individuals want to be a part of a family, they also have a strong desire to be independent. Kerr and Bowen refer to this as a differentiation of self. The authors further define this "differentiation of self", as the capacity for independent thought, feeling, and behavior. All persons need to understand where their thoughts, feelings, needs, and responsibilities end, and those of others begin. The boundaries in a family with a child diagnosed with Tourette's often become murky, because of the increased dependence of the identified patient. Cooper maintains that "coping with the daily concerns of someone with a chronic illness is, itself, a form of chronic illness." Although it is difficult, lines must be drawn that delineate the responsibilities of each family

member in a functional manner. Simply stated, it is much easier to accept responsibility for someone who is sick, than someone who is not. Conversely, it is much easier for a person with a diagnosed illness to give away responsibility. Family members that function well together will have an understanding of one another's strengths, limitations, and needs, and they will act accordingly.

The final concept necessary to understand is that of enabling. One can, at times, support the dependent behaviors of the identified patient. This is done by accepting responsibility for them, or sometimes, by not allowing individuals to accept their own responsibilities. Cooper has identified two risks in accepting more responsibility than necessary for someone with a chronic neurological illness. The first is that the person will not develop a sense of self reliance or, in Kerr and Bowen's terms, a differentiation of self. The second identified risk is that the needs and wants of the identified patient will become the family's main focus. Once this happens, the patient can and usually will use their dependent position to control the family. Enabling behavior takes on many forms, but the outcome is always the same, the enabled individual learns dependency, as opposed to independence, as a lifestyle.

All families and family members have a natural tension between wanting to be dependent and independent. Although there is no consensus on how much of one or the other each person should exhibit, it is generally believed that people are healthier when they function as separate and independent entities. For family members who are coping with the difficulties brought on by a diagnosis of Tourette's or any other chronic illness, independent functioning can be difficult. It is not, however, an impossible task and one which must be carried out. Failure to acknowledge one's own needs and emotions often leads to anger,

resentment, and depression. If one compounds the denial of one's own needs with the taking on of responsibility for an affected family member, then, not only do they inhibit their own personal growth, but also prevent the other individual from having the opportunity to develop a sense of self-reliance. Family members who acknowledge and meet their own needs are often happier, healthier, and less depressed. When someone is in this emotional position, they are more likely to support and assist those around them.

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GIFTEDNESS AND ADHD: SPECIAL NEEDS
OF SPECIAL CHILDREN

Ann H. Goodrich, Ph.D,*

Note: The information provided below applies about equally well to those children with well above average intelligence from socioeconomically advantaged homes, as well as to those who are intellectually gifted. This paper discusses children with ADHD, Primarily Hyperactive and Combined Types. It may only partially relate to the ADHD, Primarily Inattentive Type of this disorder.

Probably no children are as frustrating to parents as those suffering from Attention Deficit Hyperactivity Disorder (ADHD). They are even more frustrating than children with easily definable and obvious disabilities such as mental retardation and autism, though ADHD is certainly not as tragic. Parent and teacher difficulties in guiding, managing, and forming expectations for ADHD children stem from the characteristic inconsistency which they exhibit in their behavior and in their academic performance. The question that presents itself on a daily basis is, "Does this child fail to behave and perform appropriately because he can not do so, or because he will not do so?" This buffeting between can't or won't seems to demand from adults Solomon-like wisdom, and super-normal mind reading capabilities.

Parent expectations for performance in school by a gifted ADHD child-- that is, one whose IQ is 130 or above-- are typically greater than those for a more average child. After all, they reason, since my child is brighter than 97% of his peer group, he should be able to overcome his ADHD. But since he can't, the adults often begin to wonder if the child is not "truly gifted" or has a learning

disability such as dyslexia (in spite of reading scores at or above grade level). Additionally, a gifted ADHD child's own expectations are high, though he may mask this with an "I don't care" attitude. Everyone's disappointment and frustration only increases when a child who seems to have so much potential fails to achieve it and often functions in school at below average level. Since it seems clear from his IQ test score that the gifted ADHD child can learn and perform, it is erroneously assumed that he will do so. . . unless he is lazy, unmotivated, defiant, or emotionally disturbed. The errors in this assumption reside in a misunderstanding of the nature of giftedness and of ADHD.

Giftedness primarily represents potential, the potential to learn. Nearly all gifted ADHD children do learn - usually with achievement test scores (especially when the test is given individually) above grade placement. Attention Deficit Hyperactivity Disorder is a performance or productivity disability affecting grades. And school performance, as measured by grades, requires the very attributes that nearly all ADHD children lack. According to Dr. Russel Barkley, a pioneer in ADHD research, these attributes are persistence, organization, consistency, planning ahead, work completion, and, most of all, the ability to persevere even when the task is boring and where rewards are sparse, delayed, or nonexistent. It is hard for the parent of an undiagnosed ADHD gifted child to understand why he brings home a report card sprinkled with Ds and Fs, when the child reads two years above grade level, and has math skills of one year above. It is easy to believe this disparity is solely the result of motivational problems as traditionally understood.

In fact, motivation does enter in. Whenever a gifted ADHD child's motivation to accomplish a given task is unusually great, he can perform at least as well as most children and perhaps better.

In my experience, nearly all parents of gifted ADHD children have had their child become excited by a particular (if all too rare) school project and perform in a sterling fashion - temporarily. If the child loves to read - and frequently this is so - he may burrow in a book for hours at a time with no signs of his customary distractibility, fidgetiness, or easy frustration. The natural parental response to such behavior is, "You see, I know you can do well when you want to. Now I expect you to perform well all the time." All this succeeds in doing is establishing expectations for everyone that are nearly certain to be dashed. Thus the child who demonstrably, "can" but characteristically "won't", sets up and sustains an ongoing conflict between himself and the adults in his life which may lead to severe problems in their relationship. It may create a learned distaste for school that remains debilitating even after the child's impairment has largely been compensated for or outgrown, in late adolescence or young adulthood. (When the opportunity to specialize in intrinsically stimulating academic pursuits arrives with college.)

Dr. Melvin D. Levine, a specialist in behavioral pediatrics and a nationally-recognized expert in developmental disorders, believes that it is particularly essential for gifted ADHD children to understand the nature of their deficits and to be trained to function under moderately motivating conditions, since this type of ADHD child, by adolescence, tends to be more willing and able than others to rationalize poor school performance, insisting that school is stupid, boring, and not really important anyway. (In fact, he plans to be a writer, rock star, artist, or NFL first draft pick - any fantasy career where no academic credentials are required!) His manipulative tactics to avoid responsibility and performance need to be directly confronted and dealt with, if need be, through behavior modification treatment and counseling. As a clinician, my own experience

corroborates this opinion. However, I believe such a child's presented attitudes and beliefs are nearly always painfully acquired defenses derived from years of frustrating failure to meet expectations. It is the mythologically rare gifted ADHD child who performs poorly solely because he is "bored". These children exhibit the same performance problems in either a regular or accelerated school program, while their gifted peers who do not have ADHD manage to perform well even when insufficiently challenged and stimulated by their academic environments.

How well do gifted ADHD children learn? If parents and teachers judge what a child has acquired in skills and knowledge only by the grades he receives, they will conclude that poor grades mean a child is not learning. To date, I know of no published research dealing specifically with gifted ADHD children and learning. There are, of course, multiple studies of "underachieving" gifted students (some of whom may, I suspect, have undiagnosed ADHD in one of its forms), and gifted children who are learning disabled (ditto).

Researchers generally accept that ADHD occurs across the full range of IQs. In my experience in working with ADHD children, their productivity (grades) are all about equally affected - regardless of intelligence. However, probably ADHD more negatively and cumulatively affects learning in children in the average-to-below IQ range than in the above average range. All learning (and even IQs) can be hard to judge in ADHD children, though, because their marked inconsistencies in performance can result in spuriously low scores at any given testing time and on any type of test.

Gifted ADHD children often seem able to "sponge up" classroom information and fill in the gaps caused by their intermittent inattentiveness and impersistence of effort. (Less intellectually capable children may be less able to do so and over

the years may genuinely fail to acquire a comprehensive skills and knowledge base. For these children, ADHD may, over time, cause true learning deficits). Unfortunately, however, intelligence is usually judged by peers, teachers, parents, and the affected children themselves, by the grades they earn. And many gifted ADHD children come to regard themselves as either stupid or lazy, though they would prefer the latter characterization, since laziness - at least in theory - can be overcome.

I have also observed that gifted children are less likely to be correctly identified as suffering from ADHD or are identified at older-than-usual ages. The reasons for this are as follows:

1. Gifted ADHD children tend to remain academically productive longer than non-gifted ADHD children. Poor or puzzlingly inconsistent grades often do not become a source of concern until one of the shift points in education where there are rising expectations and requirements - typically around the fourth, sixth, or ninth grades. Sometimes, not until the college years is there sufficient academic peril to warrant diagnosis. Although other signs of the disorder may have been visible for years.
2. The gifted ADHD child frequently exhibits fewer, or less severe hyperactive, impulsive, or non-compliant behaviors at school than the non-gifted child, thus yielding fewer distressing notes and phone calls from school to home. (But often making teachers non-believers of the diagnosis of a young ADHD child who "holds it together" at school...and "lets it all hang out" at home.)
3. Although gifted ADHD children may have the social acceptance problems common to those with this disorder, they seem less likely to. If they are in a class for gifted children,

their peers may be more tolerant or able to deal more effectively with the bossiness, impulsivity, and emotional overreactions that lead to social rejection in less optimal environments. Some gifted ADHD children display excellent interpersonal judgment and awareness; this may serve to mitigate the ADHD effect in social situations and make their company prized for wit and creative ideas.

4. The parents of gifted ADHD children are usually, themselves, highly intelligent, since giftedness, like ADHD, is strongly inherited. Therefore, they may be capable of managing their children for a longer period without seeking professional assistance. This largely positive factor, though, can have the serious downside of postponing for too long the proper diagnosis and treatment.
5. Gifted children with ADHD are difficult to diagnose, in part, because they may not give the appearance of hyperactivity, distractibility, or impulsivity in the evaluation setting. Drs Barbara Ingersoll and Sam Goldstein cite research conducted at the University of Illinois showing that 80% of a large group of hyperactive children did not display obvious signs of hyperactivity in the pediatrician's office. In my own practice, I have learned to look for subtle clues to ADHD behavior which, in gifted children, may be very subtle indeed! The novelty and challenge of the testing situation with its one-on-one aspect very often effectively masks all or nearly all ADHD symptoms. I see many gifted ADHD children who have been misdiagnosed in otherwise competent professional evaluations which were aimed at pinpointing the "root of their problem" (where the "problem" is usually poor grades). Why? Because the unhappiness and anxiety resulting from poor school performance and the concomitant parent-child

conflicts have frequently been misidentified as cause rather than effect, thus compounding guilt on all sides. Dr. Paul Wender, well known ADHD researcher and author, notes that ADHD is most frequently misdiagnosed as an emotional problem resulting from marital conflicts or poor parenting.

A good prognosis, or projected long-term outcome for ADHD children has been found by most research studies to be directly related to the presence of those factors most likely to occur in the gifted ADHD child's circumstances: above average intelligence, educated and education-valuing parents, parental income sufficient to meet family needs, and lack of habitual antisocial behavior or violence. Therefore, although the rocky road to adulthood for gifted ADHD children may be strewn with some uniquely sharp-pebbles--especially the great discrepancy between school performance and potential--we can feel legitimately hopeful that these children will survive their disorder with minimal to moderate future ill effects. Like all ADHD-afflicted youngsters, these children will best be helped along that road by early diagnosis and appropriate ongoing treatment.

They will also be helped by learning to use computers. Dr. Melvin Levine stresses the frequent problems that gifted ADHD children have in getting ideas (which may be remarkably cogent, creative, and mature) down on paper and in an organized fashion. At least 80% of them have difficulty with fine motor coordination. As they ascend through the grades to levels requiring more frequent and lengthy written essays and reports, the combination of ADHD, fine motor difficulties, and disorganization often interact, together with adolescence, to produce grades even more abysmal than before. For such children, typewriters and word processors (with a spell-check program, please!) can be godsend.

Summing up, gifted ADHD children can be even more frustrating than most others because of the greater discrepancy between their performance and known potential. They are more likely to be considered lazy and unmotivated than others with this disability and to be diagnosed late, not at all, or misdiagnosed. In spite of these added complications, a good prognosis for long-term outcome is probably more favorable for gifted than non-gifted ADHD children. But early diagnosis, parental understanding, and proper behavior management improve the long-term outcome for all ADHD children.

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THE PRIVATE PRACTICE SECTOR

INTRODUCTION

THE PRIVATE PRACTICE SECTOR: ANOTHER
ALTERNATIVE FOR THE PARENTS OF THE LEARNING
DISABLED CHILD

For those interested in history, recent events have shown the world that nations that rely on private enterprise succeed where other systems fail. On a smaller scale, the success of alternate postal carriers demonstrates that there is often a need for a supplement of or alternative to the institutional provider. In educational areas, this seems to be part of a growing trend. The news commonly carries stories of plans to develop "voucher systems" or other means by which parents can purchase the educational services they prefer.

What is less well known is that there has existed an affordable and efficient private system that has evolved to meet the needs of special children. In some cases there may be private schools designed to meet the needs of the special child. Unfortunately, such schools often have difficulty surviving in the face of economic pressures and the fact that there may not be enough disabled children to support these institutions.

A fortunate alternative is the private, free-standing professional consultant. The heart of

this system is the licensed educational consultant who is a specially trained teacher and rehabilitation worker. The educational consultant usually has a Masters Degree in his/her field in addition to certifications in multiple areas of specialized work from the State Department of Education. Such a consultant may also have extensive teaching experience. The educational consultant is not a "tutor" or a teacher that supports and reviews everyday schoolwork, rather, he/she forms a program to detect and restructure the basic learning style of the student often using his strengths as a pathway to overcome weaknesses. At times, study habits, information organization and separation of necessary from unnecessary subject content is the key to his recovery. Typically, following a period of evaluation, the educational consultant meets with the child on a weekly basis and this program runs concurrently with the school year or during periods when the child is not in school.

The consulting clinical psychologist is the link between the research based scientific community, the educational consultant, and the parent. He/she is in a position to diagnose the problem with greater accuracy, using the range of intellectual, achievement, personality, and neuropsychological testing. The clinical psychologist can arrive at a definitive understanding of the child's problem and can work with the educational consultant to design a program or may link up with a neurologist, psychiatrist, or other physician to treat other kinds of problems. The psychologist can additionally provide psycho-social support, and may be helpful in circumstances where reports are necessary to meet the requirements of administrative, school, or legal authorities.

The consulting clinical social worker may be particularly helpful when there are problems in the child's home environment. Issues of child discipline, or work-study habits which may be cause for lack of academic achievement can often be handled, most effectively, by the private social worker. The social worker may also be a valuable advocate for the parent, since this professional is usually most familiar with the rights and privileges given to the exceptional child by law.

The following articles deal more specifically with ways in which these professionals can be helpful. To many, children are their most valuable asset, and investing in their future, their most important responsibility.

GETTING THE HELP YOU NEED

I: THE ROLE OF THE EDUCATIONAL CONSULTANT

Darlene K. Rostow, M.A.*

While there are a wide variety of laws that provide for special services to the disabled child and learning disabled child through public organizations, such as school systems, the actual services available may fall short of ideal. Often, school systems do not have the funding they deserve to deliver ideal programs, and often they cannot find qualified staff to run these programs. On occasion, a problem may be fairly uncommon, such as Tourette's Syndrome, and the school system lacks the resources to provide special help. In these circumstances and in others, one available answer may be the private educational consultant. The following article deals with the circumstances under which a private educational consultant may be the answer to a parent's difficulties:

1. When a learning problem is evident, but institutional resources are not adequate. Often, the educational consultant is able to give attention to working with a learning problem intensively and in a short time frame. This may not be possible in a school system which has many more responsibilities. This can be a comfort for a family who can be certain their problems are being addressed in a timely manner.

2. When further clarification of the child's educational problems is desirable. Even when an assessment of the child's educational problems has been completed, either publicly or privately, there may be a need for further information or more detailed remediation. An educational consultant can provide this service.

3. When supplemental remediation is needed. As a result of an assessment, the child may be placed in one or more special education settings. Some children have a need for continued special help after school, on weekends, or on holidays. The summer is a time when there is seldom special educational help available in an institutional setting.

4. When there is a need for a review of special educational plans. Once the school system has proposed a remedial plan, an Individual Educational Program (IEP) is generally constructed. The family of the student may have questions about this plan and may need to have it explained by an outside party. At times a parent may require advocacy, in which the family proposes to the school an alternative plan. A private educational consultant can be very important in this process since he/she may be very well-versed in the legal and administrative issues involved.

5. When the parent wishes to take an active part in the remediation. With the pressures upon school systems to serve large numbers of students, there is seldom time to instruct the parent in the special teaching techniques for their child's problems. This is where an educational consultant is very useful and can often include a parent in the private office situation in which their child is being taught. Specific instructions can be given on a day-to-day basis with the parent who can carry on the exercises at home.

In sum, the parent who has a learning disabled child has many rights within the school systems. Unfortunately, the school system may have economic, staffing, or other limitations that make ideal service delivery unlikely. The parent who wishes to employ private or family resources for a supplemental experience for their child may well look to the private educational consultant. In combination with other professionals, the private educational consultant can be an important adjunct to the child's growth and well-being.

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GETTING THE HELP YOU NEED

II: THE ROLE OF THE PRIVATE CLINICAL PSYCHOLOGIST

Cary D. Rostow, Ph.D.*

A clinical psychologist can be one of the most important consultants for the family of a learning disabled child. This professional is often in a position to provide detailed behavioral analysis, relate this behavior to its potential cause, and provide unique intervention. As mentioned in the previous article, school systems and other institutions often do not have the resources or manpower to meet all the family's needs. It is here that the clinical psychologist can give a timely, effective, and comprehensive contribution as a member of a private treatment team:

1. When there is a difficult diagnostic problem. While it is often apparent that the youngster has a learning problem, it is not always clear what that problem is. Problems may have a neurological origin, such as Tourette's Syndrome or Attention Deficit Disorder. Other children may have motivational difficulties, or may have problems in organizing their schoolwork. Still other children may have an ongoing emotional problem such as depression or a conduct disorder. The clinical psychologist has an array of tools, and the training to use them, that can answer the important question of diagnosis and treatment.

2. When the child has multiple problems. A child may be diagnosed as suffering from Attention Deficit Disorder, and this may be an accurate diagnosis. But the child may have other problems such as an emotional disorder. Separating these diagnoses is best done by a clinical psychologist.

3. When a specialized non-medical treatment program is needed. Based upon research, the clinical psychologist may have specialized intervention programs based upon learning theory-supported techniques. These behavior therapy or behavior modification programs have been shown to be useful with Tourette's Syndrome, mental retardation, behavioral tics, and other difficulties. Very few institutions have the resources to perform these services in a timely and detailed manner.

4. When a linkage is required with physicians, social service agencies, or legal authorities. As in other areas of modern life, the connection between your service specialist may be more important than the services themselves. For example, the physician may have prescribed an-anti-hyperactive medication but may have not detailed feedback on its effects. A teacher may know a child has an emotional problem but does not know the nature of this difficulty. A social service agency may need a report on a child's disability for purposes of special programming, but there is no direct source of this information. The private clinical psychologist can be extremely helpful in all these instances.

As previously discussed, institutions are not able to deliver all services needed by each child. The private clinical psychologist can be an important provider of a very central range of services that can spell the difference between a complete remediation program and one that is less comprehensive.

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GETTING THE HELP YOU NEED

III: THE ROLE OF THE PRIVATE CLINICAL SOCIAL WORKER

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The social worker is often the most experienced part of the private service delivery team from the viewpoint of working within institutions. Additionally, the private social worker may be an expert on family dynamics that emerge from the stress of living with a learning disabled child. In cooperation with the private educational consultant and clinical psychologist, the clinical social worker is a central, service delivery professional. The following is a sample of ways in which the private social worker can be of great value.

1. When family turmoil is an important part of the child's learning problems. As an expert on family therapy, the clinical social worker can provide counseling, support, and child guidance information to families who are under stress due to a learning problem of one of its members. Often this form of help can be more valuable than more technically complicated assistance.

2. When there appears to be a need for advocacy. The experienced private clinical social worker may be in the best position to assist families who have difficulty securing or understanding their rights within institutional settings. Not only can the social worker provide technical information, but can often assist in communicating with school authorities and building a case for special needs. He or she will also be informed about advocacy resources within the community.

3. When there is an unusual social circumstance. At times it may be difficult for a family with special needs, such as in cases where persons have arrived from different cultures, to make themselves understood to social or school authorities. This may be a specialized strength of the experienced social worker, and can be a highly valuable service.

4. When intervention is necessary or desirable within the home setting. An appreciation of special problems may be difficult when the only contact between the professional and those in need takes place within an office. The social worker may often travel to see how the difficulties appear at home, or in the classroom, or in other settings. This information can be vital to other treatment team members.

The private clinical social worker may be the most flexible member of the team, delivering a wide variety of useful services. With one foot in the clinical area, and another in the area of policy and institutional management, the private clinical social worker can often provide the most cost-effective and direct solution to a specialized difficulty.

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EDUCATIONAL

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GENERAL EDUCATIONAL CONSIDERATIONS

Joan Murphy, M.Ed.*

All children should enjoy school. When a child does not, something is wrong. Children show they are having problems in many different ways. Young children may react by telling parents they are sick or just don't want to go. By middle school, many may become discipline problems, exhibit behaviors sufficient to cause them to be thrown out, or sit passively in class and do little or no work. Most children would much prefer being considered unmanageable than admit to having problems doing their assignments. Tourette's Syndrome and Attention Deficit Hyperactivity Disorders (TS/ADHD) may cause many hidden disabilities which can seriously interfere with the learning process. Identifying which of these are responsible for a child's difficulties is often very hard to determine.

Although differences do exist in the options available within different school systems, too often the quality of education afforded these children will depend primarily upon the effectiveness of their parents to advocate for them. The availability of state and federal money for special programs does not assure their quality, nor that the placement of children in such programs will necessarily be in the children's best interests.

Children with Tourette's Syndrome and/or Attention Deficit Hyperactivity Disorder may find learning in an inappropriate setting virtually impossible. Even upon first entering school, they are likely to be quite vulnerable, have low self-esteem, and lack confidence. The earlier these children can be identified and taught compensatory skills, the more likely they are to develop a

positive attitude about school and achieve their academic potential. Creating an optimal learning environment necessitates a low level of stress be maintained in both the school and classroom. Materials should be age and level appropriate and only minimally frustrating. These children need to experience frequent successes. Common sense guidelines, at very least, must dictate what is or is not considered appropriate, such as keeping bus rides to and from school short and placing children in surroundings and among others with whom they feel most comfortable.

Few, if any, college or university education programs require those preparing for a career in teaching receive any specific background which might help them to understand and cope with children exhibiting symptoms of TS or ADHD. Although a touretting child may present a wide variety of tics within the class setting which, of course, can be very distracting, teachers usually will have greater problems contending with children expressing symptoms more commonly associated with ADHD, such as: immaturity, obsessive-compulsiveness, learning disabilities and poor peer relations. Regular education teachers, additionally, may have more special needs students in a large class than are found in many special education classrooms. They are most inclined to appreciate parents who support their efforts, have realistic expectations, and provide them with information which can facilitate their meeting the special needs of the child.

Children do not wish to be seen as different from other children. Those with TS/ADHD tend to be especially sensitive to wanting to "fit in". When parents of these children feel they must ask for help from the schools, they do so despite the time and effort involved, despite the invasion of privacy, and despite the fear they might be blamed for their child's difficulties. Few are not aware of the extra attention their son or daughter can

demand. Most parents ask little more than that their children be treated fairly, with kindness, and be given the opportunity to experience some academic success.

Occasionally, school systems have attempted to address the needs of these elementary and middle aged children with specially designed ADHD classes. Such classes usually attempt to parallel regular classroom studies and can provide a haven, as needed, for children not yet able to tolerate a full-day, regular program. The success of these programs, however, depends mainly upon prior planning, the availability of trained personnel, funding, and receiving the combined support of parents, teachers, and school administrators.

Special education is another option for some children. Those found eligible are afforded many opportunities which can be extremely advantageous, e.g. possible financial assistance, increased availability of support personnel, entrance into special classes and programs, tutoring, etc. Parents who are knowledgeable about the many alternatives for assistance will be better able to avail themselves of those which are most likely to best serve the needs of their children.

School-based special education programs vary widely. Finding the least restrictive, yet appropriate setting, is especially important for children with TS/ADHD who have often already experienced long-term social rejection and tend to be extremely self-conscious. Placement in special education may have the effect of further stigmatizing and alienating these students from their peers, therefore, must be given serious consideration. Parents may also be disappointed to learn that their children are assigned to classes geared for students whose needs are quite different from those of typical ADHD students. As placement of these children in an inappropriate setting may, in fact, be detrimental, parents should keep in

close contact with school personnel and be sensitive to how their child appears to be responding.

Ignoring the problems of these children will not make them disappear. Lessons which include varied activities, require student participation, and "hands on" projects, although ideally suited for students with ADHD, benefit all. Unless very severe learning or behavioral problems necessitate placement in special education, the needs of most children with TS/ADHD can best be addressed by experienced teachers in regular classroom settings. Although there are no easy answers, the cooperative efforts of parents, teachers, and students working together can do much to make the classroom learning experience an enjoyable one for all.

*Joan Murphy, M.Ed.

APPROPRIATE ACCOMMODATIONS AND MODIFICATIONS
FOR STUDENTS WITH NEURODEVELOPMENTAL
DYSFUNCTIONS IN THE REGULAR
EDUCATIONAL ENVIRONMENT

Terry L. Lovelace, Ph.D.*

If a student has been diagnosed as having a neurodevelopmentally disabling condition such as Attention Deficit Disorder, Tourette's Syndrome, Dyslexia, etc., or if a student is suspected of having such a neurodevelopmental dysfunction, then appropriate accommodations and modifications must be provided for the student in the regular educational environment.

In order for students with disabling conditions to fulfill their potential, they need:

1. a structured academic program which provides security
2. instruction and guidance in problem-solving strategies
3. high-success behavior modification programs which focuses on acquisition of appropriate study strategies and self-image enhancement (cooperative group learning is often helpful)
4. identification and removal of anxiety-producers
5. an affective curriculum focusing on-self-worth and increasing self-esteem
6. review of basic facts to ensure that insecurity is not caused by poor prior learning

7. supportive teacher guidance which may gradually be decreased
8. appropriate rewards for affective and risk-taking behaviors

Not all students with disabling conditions need to be placed in self-contained special education classes, and often, the students themselves strongly object to placement in special education settings. More mature students should be taught how to request accommodations and modifications themselves. This is important for two reasons:

1. every person needs to feel that he has some control over what happens in his life ("internalized locus of control")
2. every person with a disabling condition needs to accept responsibility for dealing with his disabilities personally so that the disabling condition does not become an excuse or crutch which prevents him from realizing his potential.

1. School personnel need to know about the student's problems, and they need to be informed in writing. Once the instructional staff has been informed of the student's diagnosed or suspected neurodevelopmental dysfunctions, then individual accommodations and modifications will be provided as guaranteed by federal and state laws. In addition, once the school is informed about the student's specific needs, the student may discover that he is eligible for special services either at the building level or through the local school board's Department of Special Education.

Special education services are available in Louisiana only if the student meets state guidelines for eligibility. These stringent guidelines are detailed in Bulletin 1508: Pupil

Appraisal Handbook which is published by the State Department of Education. However, the Chapter I program provides remediation for reading and mathematics in many public schools.

At all levels, special services for the student are guaranteed through Section 504 of the 1973 Rehabilitation Act which provides disabled people with the opportunity to attain educational and career goals. Before he enrolls in grade school or college, the student should contact the school board or special services department and obtain the name of the person who coordinates services for disabled students under Section 504. Counselors at local Vocational Rehabilitation offices can also provide information about support services.

Though many grade schools are just now learning about their responsibilities toward exceptional students, any university receiving federal funds must provide special services for disabled students. Services commonly offered include

- A. special advising, counseling, and tutorial services
- B. providing a note-taker who attends class and takes notes for the student or providing the student with a copy of the instructor's notes or the notes of a successful student
- C. requesting assistance, e.g., untimed examinations, from the student's professors
- D. use of taped textbooks and access to a reader for short assignments
- E. use of a calculator in math classes.

2. Students with disabling conditions should register early. The student's instructors should be presented with a packet of information (medical records, cumulative records, all evaluation reports, general information about students with specific neurodevelopmental disorders such as ADD and Tourette's, etc.) before the student is enrolled, and a parent-teacher conference should be scheduled before school starts every year with every teacher required to be present. The student's teachers need to know:

- A. how to contact the student's parents
- B. medications presently taken by the student, including the name of the medication, dosage, physician, possible side effects, etc.
- C. behavior modification and reinforcement strategies which have proven successful in the past
- D. the type of tutorial assistance or counseling the student is receiving and the name(s) of the provider(s)

3. The student should request preferential seating. Being seated as close to the teacher as possible in the classroom helps increase attention and may also increase level of concern. Without some anxiety, few of us would do distasteful tasks. An appropriate anxiety level can often be provided through preferential seating. Proximity to the teacher helps ensure that the student will remain on task and makes it easier for the teacher to note and correct inattention, errors, confusion about directions, etc.

Ask the teacher to seat the student next to an academically more capable student who has a nurturing personality. The disabled student should have permission to ask the "study buddy" to repeat

instructions and directions from the teacher as necessary. This saves the teacher repeating directions, and also allows both students to participate actively in cooperative learning. The impaired student can mimic the actions of the better student without embarrassment since he is receiving help from a peer. Help from our friends is usually easier to accept and less damaging to our self-esteem than having to repeatedly ask the teacher to repeat instructions and directions.

4. The use of a tape recorder in the classroom may be helpful. A small, voice-activated tape recorder should be placed unobtrusively on the teacher's desk where it can be used to record instructions and directions, or lengthy lectures. The tape recorder can also be used to answer test questions, respond to homework assignments, etc. Small voice-activated tape recorders are particularly useful because they are easier to transport and less obvious.

5. Textbooks on tape are available and useful. The Library of Congress Recording for the Blind provides services for students like The students who are registered print-disabled individuals. Contact: Recording for the Blind (20 Roszel Road, Princeton, New Jersey, 08540, (609) 452-0606) for the application/registration form, which must be signed by the physician, special education/learning disabilities teacher, or psychoeducational evaluator, who has evaluated and diagnosed the student.

Schoolbooks and other library materials, including trade books and magazines are available upon registration with the state libraries. The State Libraries for the Blind also provides free special cassette tape players which are needed to listen to the tapes. (The request form for equipment must be signed by a physician.) According to personnel from the State Libraries for the Blind, the cassette tape players are usually

sent through the mail, making for a slight delay. Immediate services are provided for those students or their parents who apply in person.

6. Time extensions will be necessary. Disabled students take longer to complete assignments. Time extensions are often necessary since these students take longer to read library materials, complete course requirements, and finish exams and in-class work. Instead of offering time extensions, many teachers simply reduce the quantity of work required for exceptional students. Emphasis on the quality of work remains the same, however.

7. Use of a proofreader to correct spelling/usage/style on assignments completed out of class will be necessary. Students who have great difficulty with spelling and mechanics, and these difficulties are attributable to neurodevelopmental disorders, suspected or diagnosed, are eligible for classroom modification and accommodation. Spelling checkers available in computerized word processing programs are very useful, as are more sophisticated computerized word processing programs which often include a thesaurus, grammar and usage checker, and punctuation checker.

Human proofreaders are even more useful if they help the student learn how to proofread for frequent errors. Proofreaders are urged to never simply correct students' errors; instead, they should point out the errors and ask the student to correct them. The use of a simple, personalized proofreading checklist which includes a list of student's most frequent composition and spelling errors appears to help many impaired students organize their proofreading and systematically check for errors.

8. Evaluation of in-class assignments and exams should exclude spelling. Many students with neurodevelopmental dysfunctions frequently have difficulty attempting to spell dictated sentences or to write compositions and responses to essay examinations. Teachers should circle misspelled words, but should not deduct points from students' grades. Instead, when tests are returned, instructors should ask these students to correct the misspellings and then return the tests. Weekly spelling assignments can be reduced by asking students with disabling conditions to learn fewer words. Using computerized spelling checkers to check spelling tests before they are graded is an appropriate way to address dyslexic and ADD students' needs. Fernald's VAKT method and the Fernald Technique for Learning to Spell are useful for teaching the spellings of specific words. Multimodality techniques result in greater learning and retention of spelling words. These techniques are also useful for teaching basic sight words, content area vocabulary words, basic math facts, etc.

9. Assistance should be readily available to aid students on exams and other materials which require sustained attention reading, and writing, and alternative testing methods are appropriate. These students often have trouble attending to and reading instructions and directions for exams; they may also experience difficulty reading the test items and writing their responses. Disabled students are allowed to take untimed tests, then follow their written exams with oral exams in order to assess the students' actual knowledge and understanding of what has been learned. Otherwise, Section 504 of the Rehabilitation Act of 1973 may be violated, since the students' grades may reflect the extent of their disabling conditions and not the extent of their knowledge.

Classroom teachers should never give higher grades to exceptional students than they deserve simply out of pity. At some point every disabled student will have to demonstrate that he has learned what has been taught. However, sophisticated and humane measurement techniques should be employed in testing students' knowledge and skills. For example, instructors, by law, are allowed to

- A. offer untimed, oral examinations
- B. assign short answers or outlines of answers instead of essay questions
- C. use oral questions and answers instead of written examinations
- D. re-schedule consecutive testing sessions since disabled students often become extremely confused when attempting to study for two examinations at the same time
- E. read tests aloud to students as they follow along on their copies
- F. allow students to work math tests item by item at the chalkboard rather than responding to many items on one page
- G. present students with a single item or problem in order to reduce the number of stimuli presented and to reduce test anxiety
- H. ask students what kinds of exams they prefer to take and administer that type of exam

However, the burden of demonstrating acquisition of knowledge and skills should be placed directly on students. If they cannot

demonstrate acquisition of knowledge when tested appropriately, then the grades must reflect that lack of knowledge. The option of a retest should be offered to an exceptional student if the student is willing to continue attempting to learn the material.

10. **Notetaking strategies must be modeled and taught.** Seat students with neurodevelopmental dysfunctions next to helpful students who take good notes. Ask the disabled student's parents to get a carton of 2-ply NCR paper at a discount warehouse or office supply warehouse (prices are cheaper there). The better student makes notes using the NCR paper and then gives the student who had difficulty learning the carbon copy. The disabled student can transfer the notes into his notebook at home later. Students with disabling conditions are still responsible for taking notes in the classroom, but they can augment their notes from the carbon copy after school then have an excellent set of notes to use to study for exams.

Instead of asking students with disabling conditions to copy from the chalkboard, provide them with photocopies of the instructor's notes, detailed study guides, and modified outlines in order to help them learn the material.

11. **Emphasize acquisition of the processes for learning, not simply acquisition of memorized material.** Unlike many students who learn how to learn on their own, students with neurodevelopmentally disabling conditions have to be taught how to learn. Grade school instructors can use the Guidelines for the Process of Writing to teach composition skills, Fernald's Technique for Learning to Spell to teach the spellings of vocabulary words, Fernald's VAKT method to teach basic math facts, etc. The student with neurodevelopmental dysfunctions often has to be taught, step by step, how to learn.

12. Teach social skills as well as academics. Students with neurodevelopmental disorders often have difficulty acquiring appropriate social skills, the "people" skills they need in order to have friends and to be friends. Like all children, developmentally delayed students need to learn how to respond appropriately in the classroom, on the playground, on the school bus, etc. Social skills are taught the same way academic content should be taught, by

- A. focusing the student's attention on what is to be learned (state the objective and the exact behavior the student will be able to demonstrate at the end of this lesson)
- B. explaining why it is important that students master the skill
- C. modeling the exact behavior the student should learn
- D. checking for understanding by guiding the student through a few imaginary situations
- E. asking the student to demonstrate the social skill in a real-life setting and report what happened
- F. keeping track on a chart for 2 weeks the daily use of the social skill in the real-life settings, refining the behavior until the social skill becomes automatic
- G. introducing the next social skill and repeating the cycle

Listed below are professional materials I have found useful; these same materials are also appropriate for parents and teachers who wish to help their children develop appropriate social

skills. However, for these programs to be successful, parents and teachers must faithfully and conscientiously follow instructions. I have found children respond must better to social skills training programs when they are appropriately medicated (as determined by the physician and parents) during instruction and practice sessions.

Becker, W. Parents Are Teachers: A Child Management Program. Champaign, Illinois: Research Press, 1971.

Faber, A. & Mazlish, E. Liberated Parents, Liberated Children. New York: Avon, 1974.

McCarney, S.B. (1989). The Attention Deficit Disorders Intervention Manual: School Version. Hawthorne Educational Services, P.O. Box 7570, Columbia, Missouri 65205. Telephone: 1-800-542-1673. Approximate price: \$22.00.

McCarney, S.B. (1989). The Parents' Guide to Attention Deficit Disorders. Hawthorne Educational Services, P.O. Box 7570, Columbia, Missouri 65205. Telephone: 1-800-542-1673.

Osman, B. No One to Play With: The Social Side of Learning Disabilities. Novato, California: Academic Therapy Publications, 1982.

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Walker, H.M., McConnel, S., Holmes, D., Todis, B., Walker, J., & Golden, N. (1988). The Walker Social Skills Curriculum: The ACCEPTS Program (A Curriculum for Children's Effective Peer and Teacher

Skills). Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758.

Walker, H.M., Holmes, D., Todis, B., & Horton, G. (1988). The Walker Social Skills Curriculum. The ACCESS Program. Adolescent Curriculum for Communication and Effective Social Skills. Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758.

13. Do not expect students whose disabling conditions include memory problems to remember more than one instruction at a time or to pay attention for long periods of time. Instead, encourage them to become list writers, students who make "Things to Do Today" lists for the day for activities at home and at school. Teach the students to prioritize the activities and then cross them off the list as they are completed. An incentive system, based on making the list, prioritizing the list, and completing the activities should be instituted for completion of these tasks. Design the reward system around things students most enjoy doing. If you are not sure what motivates, ask. Most students can tell you what they are willing to work for.

14. Help disorganized students learn organization skills, particularly those necessary for school work. Students who are easily confused by school tasks (such as managing homework) should keep all of their notes for all of their school subjects in a single large 3-ring binder divided into sections by subject areas. A small plastic pouch which fits on the 3 rings should be purchased to serve as a storage compartment for pencils, erasers, protractor and compass for geometry problems, ruler, calculator, etc. This single notebook and all books and other school supplies should be stored in a large, sturdy booksack and carried everywhere so that students always know the

location of their books and other learning materials.

Do not give students with neurodevelopmental disabling conditions storage space in a locker: the locker becomes a "catch all" dumping ground for things needed in class, including current homework assignments which may have been completed. Most elementary and secondary schools have rules forbidding students to leave class to go to their lockers to get materials they have forgotten. Instead, students usually receive a grade of zero.

The booksack should be carried wherever students go during school and should be taken home every afternoon. Then students will have everything they need to complete homework: the homework assignment pages, textbooks, notebooks, etc. The booksack should be placed every night in the doorway each student will use to exit their homes for school (for one student, the kitchen door; for another student, the door into the garage, etc.). If the student trips over the booksack on the way out of the door to go to school, the student will be more likely to remember to take the booksack with him.

When the time comes, parents should purchase file cabinets for their children. The file cabinets serve as a management storage system for class notes, graded papers and homework materials, and other study materials are kept.

15. Contact Educational Testing Services and the American Testing Program for information about alternative testing procedures for the Scholastic Achievement Test (SAT) and American College Test (ACT). When high school students with neurodevelopmental dysfunctions enter the second semester of their sophomore year, contact:

Educational Testing Service
ATP Services for Handicapped Students
CN 6602, Princeton, NJ 08541-6602
(609) 921-9000

American Testing Program
P.O. Box 168
Iowa City, IA 52243
(319) 337-1000

If students with disabling conditions begin taking these tests early, they can re-take the entry exams if the students do not qualify the first time the test is administered. Many university and college testing centers serve as testing centers for special administrations of such standardized examinations. Call your local college or university's Counseling and Testing Office and ask for more information.

16. In order to succeed in school, neurodevelopmentally disabled students must develop automaticity in basic fact learning, such as instantaneous recognition of the basic sight words, basic math facts, spelling of common words, etc. These students must overlearn necessary information such as basic sight words and math facts, since overlearning helps develop automaticity, and automaticity requires less energy expenditure. Most students with ADD and Tourette's Syndrome experience malaise and fatigue when they try to learn. Any learning task requires mental energy, but learning new material requires even more effort and energy. If students practice until their response rates are quicker, they will be able to devote more energy to other learning.

For example, once the basic sight words can be recognized instantaneously on sight, then the focus can shift to comprehension of the basic sight words when they are combined in phrases, sentences, and paragraphs. Drill and rote learning tasks are often disliked by students with neurological

impairments, but are useful when learning basic skills to automaticity. Time demands should be placed on neurologically impaired students only when the material is well-learned.

17. Break visual and auditory material into smaller parts, and present instructional content in a structured, sequential, logical order. Break the new information into groups of 3, drill and practice on this group; then overlearn the second group of 3; then review the first 2 groups of 3. Continue until all the material has been mastered.

A sample lesson follows for teaching students the 7 days of the week in order:

- * Divide the task into 3 sets: [Monday, Tuesday, Wednesday], [Thursday, Friday, Saturday], and [Sunday].
- * Drill the student on pronouncing and spelling the first set of 3 words: [Monday, Tuesday, Wednesday].
- * Drill the student on spelling and pronunciation of the second group of 3 words: [Thursday, Friday, Saturday].
- * Review the spelling and pronunciation of the first 2 sets: [Monday, Tuesday, Wednesday] [Thursday, Friday, Saturday].
- * Drill the student on the spelling and pronunciation of the third set: [Sunday].
- * Review the spelling and pronunciation of all 3 sets: [Monday, Tuesday, Wednesday], [Thursday, Friday, Saturday], [Sunday].

Use many repetitions to ensure overlearning. Be careful not to overload the student's visual short-term memory; otherwise, the student could become very confused. If a set of 3 is too large a set for an impaired student, reduce the set size to 2 items or even to single items. Request that instructors either reduce the amount to be learned or increase the time to learn the required material.

18. Teach students with learning problems to study content in the same way the material will be tested. If the weekly spelling test is dictated, then the spelling words can be tape recorded by the student, using this model: "Number 1. Spell cat. The cat ran down the street. Cat. Number 2. Spell only. I am not the only child with brown hair. Only." The student can listen to the recording and then write the words, then compare the "test" results with answer key (the same words in the same order spelled correctly by an adult or older student who has written the words legibly in cursive).

Students with neurodevelopmental disorders are often confused by the difference between printed and handwritten words. Even though the words are spelled with exactly the same letters in exactly the same order, the words do not look the same. Some students with perceptual dysfunctions are unable to translate typeset words into cursive or manuscript handwriting. Providing a model of spelling words written exactly as students are to write them on the spelling test allows students to compare their handwriting with the "correct" model to see if the two match.

Some students have improved their grades and learned more by following this study process:

- A. Study using models for "correctness" provided by parents, teachers, or "study buddies."

- B. Prepare a test that looks like the model and test yourself.
- C. Correct your mistakes using the model for "correctness" as a guide to the right answers.
- D. Repeat whatever you are learning out loud as you rewrite it several times.
- E. Test yourself again.
- F. Repeat the cycle until you can demonstrate mastery of the material that will be on the test.

19. Demonstrate students' progress on progress charts. Make a chart for the student which shows how many vocabulary words or math facts or social skills have been mastered. Use stars or "smilie faces" or check marks to help younger students understand that they are learning. As students grow older, the format of the chart changes, until, by high school, the chart becomes a record showing the number of points the student earned on all tests, quizzes, projects, etc., in each subject area. High school students should compute their own grade point averages so that they know their standing in every course at all times.

20. Use behavior modification and contingency management techniques to teach students organizational skills. Instructors of students with neurodevelopmental dysfunctions should make consistent, realistic, firm demands for quality performance. School psychologists, guidance counselors, social workers, and behavior management therapists can help students and their parents develop appropriate systems for managing homework, studying for exams, taking notes, etc. However, a reward system must be instituted so that the student receives concrete benefits for participating in the system.

Parents can cooperate at home by designing a personalized contingency management program so that the student receives rewards after completing chores or homework correctly and on time. Initially, every step of every task has to be closely supervised, with step-by-step assistance provided as the student runs into problems. So work on one task at a time. With some children, the task will have to be subdivided and addressed in even smaller increments. As the student learns the task to automaticity, then the parents and/or teachers can gradually withdraw assistance, but as long as high expectations are established for quality performance. Check the student's work frequently, so that quality performance is a reality and not an assumption.

21. Help students with neurodevelopmentally disabling conditions conquer extreme anxiety and reluctance related to learning. These students often demonstrate high anxiety and impulsivity related to school learning. Very impulsive students have difficulty because their production and growth on new material is often slow, and they are left behind. This generates anxiety which makes them even less prone to take learning risks. Students like this generally do well in structured programs which provides security. Also important are establishing classroom routines and maintaining such routines. Help students with neurodevelopmental dysfunctions acquire problem solving strategies. For example, ask leading questions to guide students through the learning process. Utilize behavior modification programs that ensure high success on the students' parts, and include self-image enhancement and self-direction as fundamental components of the program. Help students identify and remove anxiety producers. Provide honest praise for effort and quality work. If high anxiety persists, ask a professional for assistance; therapy may be necessary.

Provide an affective, humanistic curriculum which focuses on the child's or adolescent's worth as a person. Ask the instructor to teach creative problem solving methods such as those developed by Torrence and Renzuli (brainstorming, cooperative problem solving, etc.). Only children who have experienced many successes are willing to attempt a task which might result in failure. Praise students with neurodevelopmental dysfunctions every time they are observed behaving appropriately or taking an appropriate risk when trying to learn.

22. Help developmentally delayed students learn how to modify inappropriate behaviors. When they act impulsively, remind them to "Stop, look, and listen." Lead them through a problem-solving process which will help them learn to make wiser choices by asking specific questions which illustrate the consequences of impulsive actions.

23. Teach neurologically impaired students to type as soon as possible, then to use computer software programs such as word processors, spell checkers, and proofreaders for punctuation and grammatical errors. Dr. Richard Bloomer, Chairman of the School Psychology Department (Box U-67, University of Connecticut, Storrs, Connecticut) has developed a superior "reading through typing" program for use with students with neurodevelopmental disorders which has proven to be very successful in teaching these children both phonics and spelling skills.

24. Allow disabled students to use calculators and other electronic devices during math classes and on math exams. Students with neurodevelopmental disabilities often make errors when working math problems resulting from deficits in visual/spatial perception and/or memory dysfunctions. Do not administer timed tests to this group of students until they have demonstrated mastery of the content being tested. The students should be able to correctly answer at least 90

percent of questions presented about the material; otherwise, the students should return to drill and rote memory exercises. Students can use the VAKT method to memorize the basic math facts (addition, subtraction, multiplication, and division).

25. Contact the Orton Dyslexia Society for further suggestions related to teaching methodology appropriate for dyslexic students. The Orton Dyslexia Society's mailing address is 724 York Road, Baltimore, Maryland 21204; telephone (301) 296-0232. The society was founded on the belief that all dyslexic students can realize their potential if they receive quality instruction designed to meet the needs of the individual student. Many of the teaching techniques espoused by the Orton Dyslexia Society are appropriate for other students with neurological impairments.

Summary

The best predictors of the future success and the quality of life for neurologically impaired students are

- * the family's socioeconomic status
- * the parent's child-rearing practices, the emotional climate of the home, and the extent and severity of the family's dysfunctions
- * the student's inherited cognitive potential
- * the student's emotional stability and the extent and severity of aggressiveness and hyperactivity exhibited by the student
- * the student's acquisition and utilization of appropriate social skills

- * early detection and comprehensive treatment of all of the student's neurodevelopmental dysfunctions and disabling conditions.

Currently, appropriate medical treatment for students with neurodevelopmental dysfunctions focuses on

- * appropriate utilization of medication prescribed by physicians supported by other health care professionals who document the individual's responses to prescribed medications and support the individual and family in following the physician's orders exactly
- * behavior management reinforced through individual and family counseling sessions
- * cognitive therapy
- * provision of appropriate accommodations and modifications in the traditional educational setting for students with neurodevelopmental dysfunctions
- * acquisition of coping strategies which allow disabled students to compensate for neurodevelopmental dysfunctions
- * utilization of a case manager to ensure coordination of all services provided for the student and communication among all professionals involved in this case

If these accommodations and modifications are provided in the regular education environment, and the student still is unable to realize his/her potential, then the parents or legal guardians should request appropriate evaluation by the school board's Department of Special Education. An

example of such a letter of request for evaluation is provided at the end of this article.

Should the system prove reluctant to cooperate, contact the State Department of Education and ask for the Quality Assurance representative in the Special Education Division. Express your concern both in a telephone conversation and in writing. Should your child still not receive services, contact the regional Office of Civil Rights and file a complaint.

Terry L. Lovelace, Ph.D., Inc., April 15, 1992. Permission is granted to reproduce this article in its entirety for nonprofit use as long as credit is given to the author.

*Terry L. Lovelace, Ph.D.
Terry L. Lovelace, Ph.D., Inc.

**CHECKLIST: QUESTIONS TO ASK IF YOU BELIEVE YOUR
CHILD HAS PROBLEMS WITH EDUCATION**

ACED and Project PROMPT*

- * Is the child making acceptable grades and/or progress in school?
- * What explanations does the child give for poor work?
- * What explanations, if any, does the teacher give for the child's poor work?
- * Are grades poor only in some specific subjects? If so, is there a particular type of activity that is most difficult for the child? (For example, reading, writing, spelling, math).
- * Does the child seem to remember and repeat information orally, but have difficulty putting it in writing?
- * Does the child forget things which he or she previously learned?
- * Does the child have physical mannerisms that might interfere with learning, such as inability to sit still, short attention span, inability to concentrate?
- * Does the child have problems with physical coordination (such as running, skipping, hopping) or with fine motor skills (such as using small objects like pencils, video game controls, tying shoes)?
- * Is the child easily frustrated? How does the child act when frustrated?

- * Is the child frequently angry? Does the child have frequent emotional outbursts or temper tantrums? Does the child become physically out of control?
- * Does the child cry more than most children his or her age?
- * Has the child had any unusual, repeated, or serious illnesses or injuries? If so, has the child been medically tested for any harm caused by them? Did the child's school performance change dramatically after such an illness or injury?
- * Have the child's vision and hearing been recently tested? (If routine tests do not indicate problems, but it seems the child does not see or hear well, additional testing is suggested.)
- * Does the child have difficulty with speech or language? Does the child speak less clearly than children the same age? Does the child use more immature language than children of the same age?
- * Does the child have difficulty following verbal instructions?
- * Does the child like school? Why or why not?
- * What are the teacher's answers to these questions?

Reprinted from Educational Rights of Children with Disabilities in Louisiana - A Guide for Parents

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THE SCHOOL NURSE

Annette Augustus, R.N.*

The school nurse can act as an invaluable liaison between the parents of the students with various medical conditions and school personnel. Especially in the lower grades, the nurse can aid in the detection of both Tourette's Syndrome and Attention Deficit Hyperactivity Disorder (ADHD). The earlier the identification of these children, the more likely the possibility of preventing or greatly reducing many of the problems that can occur later in life as a result of these conditions.

Teachers who suspect a student might be exhibiting symptoms of either of these disorders, i.e. verbal or motor tics, short attention span, hyperactivity, etc., should share their suspicions with the school nurse. If after checking with others also familiar with the child and/or observing the child's behaviors sufficient concern is established, the nurse will call the parents to recommend an evaluation be done by a qualified physician.

Parents of children previously diagnosed should contact either the school secretary or nurse prior to the student's admission into a new school. If the child must take medication while on the school campus, it will be necessary for the proper forms to be obtained and filled-out, usually requiring completion by both parents and the attending physician. It is extremely important that all children with medical conditions visit their doctors for periodic check-ups, and that the physician provide the school with information concerning the possible effects of all prescribed medications currently being taken by the child.

The school nurse can also help foster understanding by teachers regarding the nature of the symptoms of Tourette's and ADHD, as well as provide information regarding the various stress-inducing situations which might result in the escalation of these symptoms and associated behaviors. Parents who are aware of particular difficulties facing the child, such as an impending divorce or move, should not hesitate to speak openly with the nurse. Communications concerning specific problems can be kept confidential while the nurse, in alerting school personnel, can often help defuse potential crisis situations before they arise.

Teachers, especially in the lower grades, may find the use of a "Time-out" place helpful to students experiencing increased symptoms. Some school nurses may, in fact, recommend teachers send the student to the nurse's office as an alternative to the "Time-out" area.

The primary goal of the school nurse, regarding children affected by Tourette's and/or ADHD, is to provide information to school personnel about these conditions, secondary problems, and the possible effects of prescribed medicines. The nurse can also ensure that consistency of care be maintained between the physician's office, home, and school.

*Annette Augustus, R.N.

**THE ROLE OF THE SCHOOL SOCIAL WORKER
IN WORKING WITH STUDENTS WITH TOURETTE'S
AND ADD/ADHD**

Carolyn Bowman, MSW, BCSW*

A social worker is exactly what the name denotes, a person who attempts to use all the resources available in the environment to effect changes in the life of an individual who needs help. Resources include, but are not limited to, the use of the individual's inner resources and coping mechanisms to achieve growth. However, social work philosophy also takes into account the fact that changes in coping skills are sometimes lost or destroyed, if the support systems in which they operate do not change. In the school setting the social worker's job is to marshal all the resources available and use them to enable the student who is "different" to survive and succeed.

It is generally easier for people to relate to the visible evidence of a disability than it is for them to accept behavioral problems -- especially if those behaviors are also found in the behavior of so called "normal" individuals. Teachers can intervene and deal with problems they can observe. A child who roams the room or has a "tic" can easily be identified. However, impulsive behaviors such as blurting out, interrupting, touching inappropriately, fighting, or behaving in silly or unusual ways are most often associated with willful attention-getting tactics. In addition, problems with disorganization, forgetfulness, incomplete homework and/or class work, inattentiveness and distractibility are often seen as controllable behaviors. Any and all of these problems occur to some degree in students without Tourette's or ADD/ADHD, but the frequency and severity of the

behaviors in affected students seems to indicate a connection with the condition.

For many students who must live with Tourette's Syndrome, their impulsive, compulsive behaviors are, therefore, most often as debilitating as their motor and vocal tics. Tics are dramatic in nature, but unless they are excessive or repulsive (spitting, gesturing, cursing, etc.), they are more acceptable as forms of a disability than behavioral problems. Students with ADD/ADHD have most of the same impulsive difficulties and experience many of the same difficulties in the school system.

The child whose impulsive or compulsive act has created a problem causes a dilemma for service providers. They generally feel that a decision must be made about whether the behavior was related to the disability or a deliberate misbehavior.

There is a fine line between what is within the confines of so called "normal" behavior and what crosses over into something else. Almost every abnormal behavior has its base in normal behavior. For instance, everyone is sometimes a little "paranoid", but they don't see "Indians behind every tree." Impulsive-compulsive behaviors are often subtle. It is difficult to determine when behaviors spring from normal reactions which are allowed free reign, and when they result from a student's inability to put a "stopper" on impulses that should be curbed. Students with Tourette's and ADHD also vary along a continuum, just as the average person, with minimal involvement and good control, to a severe condition with poor control.

Dealing with inappropriate social behavior at school is probably the most difficult problem facing the people responsible for these students. Reactions to the child's behavior swing from total denial of the relationship of their behavior to the

physical condition, to insistence that all negative behaviors are attributable to their disorder.

Because parents of students with either TS or ADD/ADHD are sensitive to their children's problems, and because they are most often put on the defensive by others about their children's behaviors, they may lean toward blaming the "condition" for these difficulties. This takes the pressure of "blame" off everyone. Parents have also seen the changes that medications have been able to make over the years, sometimes controlling, sometimes exacerbating problems. Parents have the unenviable job of balancing school accusations and demands with their real needs and problems of their child. They are under pressure to "make the child behave" on the one hand, and not exert undue pressure on the other.

Teachers, school administrators, and other school service providers are faced with the task of maintaining school discipline and providing a learning atmosphere for all children, including disabled students. They have the problem of setting up rules for discipline that are equitable, fair, and still allow the learning process to continue. Because of frequency and intensity of their problems, school personnel often feel that Tourette's and ADHD students are excused too much and that their actions are really deliberate. They feel anger when the child seems to be "getting away" with bad behavior that is excused by his disability. They also feel anger at being powerless to discipline as they would others.

At this point, someone with information about the disability and hopefully without an "ax to grind", can look at problem situations and try to help all parties to come to a resolution that will be fair and growth producing for all concerned. The social worker can perform that task by acting as a buffer to absorb the anger and interpret feelings into messages that work to create positive

change and that furthers understanding, but does not carry blame.

Looking for blame is counterproductive. It is not imperative that one learn whether an act was deliberate or the result of an impulsive act. It is important that the students with ADHD or Tourette's learn the consequences of their behaviors. They are headed for the "real world" where inappropriate behavior will not be willingly tolerated. Behaviors which are unacceptable and violate the rights of others carry definite consequences. It is important, however, that consequences be meaningful and teach, rather than punish. It is also important that the consequences do not exacerbate problems that are caused by their disability. For example writing endless, meaningless "lines" is inappropriate for a student with ADHD or TS and teaches them nothing. An essay of limited words which helps them reason through problems and teaches them to find workable solutions would be more appropriate.

Behaviors which simply inconvenience or irritate the situation in the classroom (i.e. noises from the tics, etc.) should be looked at for solutions and not for blame or consequences. Modifying the environment or the schedule may be a way to repair or improve the situation.

If a child continues to exhibit serious behavior problems, despite all efforts to deal with them in the regular class situation, he might be referred for evaluation by a pupil appraisal team. This team would determine whether the child could meet the criteria outlined by the state for students who are classified as "disabled". If the student has no other, more serious problem, the classification which most are given is "Other Health Impaired".

Once a child becomes "identified" an Individual Education Program (IEP) is written

specifically for him. In the IEP, modifications are planned which address any problem caused by the disability. These modifications might be in the regular education setting or in a special education program. They would include behavioral, disciplinary, and academic goals.

Social workers are usually members of the professional teams that evaluate and identify exceptional students. They are often members of the School Level Committees, where they serve as contact person from the Assessment Team. They are also, generally, members of the IEP committee and help make appropriate recommendations for the educational program.

Social workers can be of help to students with Tourette's and their families in several ways. Perhaps the most important way is by knowing, and sharing information about Tourette's Syndrome and ADHD with teachers and parents. Not only can this knowledge help teachers identify affected students, but it can help teachers, parents, and students understand and deal with the condition. With information regarding available resources, social workers can direct families to places where they can get support, treatment, and the services they need. Helping to find others who will become members of a support system within the school and the community is also an important goal of the social worker.

Not every person who has Tourette's or ADHD has problems severe enough to require modifications in their school program. The social worker may, through counseling help the child, the teacher and the parents make changes which can resolve problems before they get to be major ones.

Because of the tremendous amount of negative feedback that one gets, the student with Tourette's and/or ADHD needs someone outside the family who believes in him and helps him feel that he is

important and valuable. The primary goal of the social worker should be to encourage self-esteem. It is the directive of all those who work with these students. Somehow, the students must come out of their school experience with their dignity intact or all the other teaching they receive is worthless. Counseling can sometimes help achieve that goal.

School systems in different areas and in different states vary in the services offered by school social workers, but most have these professionals and parents may request their services. This is usually done by contacting the student's teacher or principal and requesting a referral through the school procedures.

For parents of children with TS or ADD/ADHD, the information which is important is that social workers have knowledge and skills that may be of help in dealing with a child with a disability. This is also true for the adult who continues to have social/emotional "baggage" left over from dealing with a disability or who have unresolved feelings about current problems. Social workers have knowledge about coping skills, functional and dysfunctional behaviors, parenting skills, and behavior modification techniques. Most of all they have the ability to "listen".

*Carolyn Bowman, MSW, BCSW

TOURETTE'S SYNDROME AND SPEECH THERAPY

Judy T. Eilts, M.A., CCC-Sp.*

One of the most distinctive and perhaps disturbing aspects of Tourette's Syndrome is the presence of involuntary vocal tics and coprolalia (the explosive utterance of obscene or provocative words or phrases). Contrary to popular belief, these symptoms do not constitute the type of speech disorder amenable to treatment by a speech therapist. It is well advised that the parent become familiar with the characteristics indicative of a need for speech and/or language therapy.

Disabilities of speech fall into the categories of articulation, voice, and fluency. In articulation disorders, speech sounds may be omitted ("go" for "goat"); replaced by a substituted sound ("wun" for "run"); or distorted. Distortions are substituted sounds which cannot be identified as any known consonant or vowel in the language. Children with multiple articulation errors may have speech that is unintelligible.

Voice problems may be manifested in the areas of pitch (highness or lowness of the voice as related to the musical scale); loudness (strength or weakness in volume); or quality (breathlessness, harshness, hoarseness, or nasality). Physical concomitant, such as vocal nodules, papillomas, or polyps may be present.

Fluency disorders, commonly known as stuttering, are interpretations in the smooth flow of speech. These problems are characterized by repetitions ("pu-pu-pu-pig"); prolongations ("sssssssnake"); and/or hesitations ("uh...I...uh...I want...uh"). Struggle behaviors, such as lip tremors, eye blinks, or foot tapping

may accompany the dysfluencies as the speakers attempt to push through their blocks.

Among the problems unique to TS children is the repetition of their own words or those of someone else. While this symptom may sound like stuttering, it is actually more echolalic in nature.

In addition to articulation, voice, and fluency disorders, speech therapists also remediate disorders of language. Whereas speech refers to the actual spoken word, language is the ability to understand and transmit ideas. Disabilities in language can be related to some form of central nervous system malformation or to environmental factors such as inadequate linguistic models. Expressive language disorders generally affect the areas of vocabulary, size, sentence length, and the use of grammatical structures. Receptive language disabilities may manifest themselves as difficulty interpreting the meaning or finding the humor in a story.

If a child exhibits any of the described speech or language characteristics, speech therapy may be indicated. Referral to a speech therapist can be made through the local public school system or through the child's pediatrician.

*Judy T. Eilts, M.A., CCC-Sp.

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**COUNSELING STUDENTS WITH TOURETTE'S SYNDROME
and/or
ATTENTION DEFICIT HYPERACTIVITY DISORDER**

Joan Murphy, LPC*

Children severely affected by Attention Deficit Hyperactivity Disorder, with or without Tourette's Syndrome, can sometimes be difficult to tolerate for even short periods of time. Their level of energy, lack of attentiveness, impulsivity, and unrelenting perseverance can often try the patience of even the most saintly. Typically, they are socially ostracized, especially through their elementary and middle school years. During this time, their energies may well appear to be dissipated in unproductive pursuits and on a wide array of quickly abandoned interests. Despite seeming to be irrepressible, these children tend to lack self-esteem and require constant approval and reassurance.

In general, students with TS/ADHD seem to do best when they are scheduled for the more academic courses in the morning and physical education or athletics in the afternoon. When possible, two studies particularly difficult for the student, should not be arranged in succession. Shops and other vocational, "move about" classes also may offer the child respite from the build-up of stress. Children on some of the medications typically prescribed may require more bathroom and water fountain privileges.

Teachers who are inclined to fare well with these children are experienced, flexible, consistent, structured and have a good sense of humor. Classroom difficulties presented by children with either TS and/or ADHD may vary greatly in kind and severity. Students with Tourette's may rarely exhibit any discernible tics,

and mildly affected children with Attention Deficit Hyperactivity Disorders, especially in courses with many "hands on" activities, may need no special assistance. Lists are available (such a list of "Suggestions for Teachers" has been included in the article following) as to the possible ways the learning situation can be adjusted to meet the needs of individual students. Parents, teachers and students can be given a copy of such a list by the school counselor and asked to identify two adaptations each feels might provide the student with the greatest assistance. When one or two can be agreed upon, they should be attempted, and later evaluated. Those adjustments found most beneficial can be retained, while new ones considered.

Antagnosims can easily arise between parents and teachers when requests made are insensitive to the other's difficulties, involve one-sided responsibilities, or are unrealistic. As an illustration, parents will often push teachers to commit to checking that the student has copied the assignment correctly, write it down for him, or briefly evaluate how the child did during each class. Although some elementary and middle school teachers are successful with this type of program, these teachers have usually set aside time for this activity during class. Most such attempts to force, especially teen-age students, to do their work, not only fail but further strain the child-parent relationship, which is believed to be of far greater importance. Teachers may also become aggravated to discover that, despite the added work and diligence required for them to monitor the work of these students, most parents will have as great a problem remembering to check for these reports and assignments, as do their children in bringing them home.

Some students do respond well to having their work initially reduced, both in difficulty and amount, to below what they are capable. Regular work sheet and test problems can just be "starred"

to indicate the ones teachers wish students to complete. Teachers can then enlist the students' help to determine where they are experiencing the greatest difficulties and what they are able to accomplish.

In general, when these children are asked what they do well, many are likely to mention Nintendo-type games and, perhaps sports. Video games are understandably appealing, as are fast paced, maintain high interest through many senses, challenge without threatening, offer frequent rewards for successful efforts, and afford the child control over much of what occurs. Computer assisted learning programs are being successfully utilized as an important educational tool with both ADHD and TS affected students. Teachers should be forewarned not to be too disappointed, if a child appears to improve greatly for a day or a week, and then seems to revert back to many of his old habits the following week.

A tourettor who may become particularly loud or can have obscene words or gestures in his tic repertoire is best seated in front of the class, as better able to concentrate on the teacher and less likely to affect the learning environment. Students with Tourette's may find walking to the back of the room or retreating to the bathroom to expel tics, when needed, can help reduce their frequency or intensity. Both motor and verbal ticking commonly become much worse when the student is placed under stress. A teacher might well discover during an exam that a tourettor's verbalizations, not only become louder and more frequent, but that they may include answers to the test. Other students in the room may find concentrating with such noise difficult. As at this time the student might also feel uncomfortable about having only the sounds of his lone verbalizations break the classroom silence, if he can be trusted, arrangements might be considered to

allow him to take the test in the library, special education room, or private area.

The majority of teachers can be credited with doing the very best which is possible, although they may have to be reminded that the criteria for success with these children may be unlike those for other students. For example, quite significant gains might merely entail a child's ceasing to exhibit undesirable behaviors, such as leaving the campus without permission, cursing teachers, fighting with peers, or acquiring new ones, like scoring 80% on a test, completing an essay paper, joining a soccer team, or taking a date to the prom. As many classroom modifications and techniques are possible to help these students, teachers can often profit most by sharing their failures and successes with one another.

Counselors can accomplish much by being able to initiate positive communications between parents and teachers, and to help each gain an appreciation of the world as these children, with their limitations, may perceive it. Ideally, before trouble arises, both parents and teachers need to have a realistic picture of the difficulties the other could encounter, and what each can reasonably be able to expect.

Too frequently, because of the types of behaviors symptomatic of ADHD, these children have experienced their greatest success in gaining the attention of others with negative or problematic behaviors. Those involved with the care of these children may, inadvertently, reinforce such roles by recounting examples of the children's escapades. Additionally, parents who make negative remarks about schools, teachers, or education in front of their children may also discover such knowledge provides the children with the know-how to pit them against school personnel, avoid having to face uncomfortable situations, and to take responsibility for their actions. Parents and

teachers need to establish means of keeping in touch and safeguarding against walls being built between them by these children. Generally, counselors can encourage positive communications between parents and teachers and should rarely become involved, except to smooth out snags which might arise in their relationships.

Education may not, initially, rank high on a counselor's list of priorities when attempting to help children severely affected by either TS and/or ADHD. Their lack of self-worth, low tolerance for frustration, disruptive behaviors, and inability to get along with others, especially of their age, may well be considered far more in need of attention. Dysfunctional students must be able to see themselves in positive roles as worthwhile individuals. Despite many possible failures, involvement of these children in activities of many types, both within and outside of the schools should be encouraged, for locating even one significant avenue of accomplishment may completely change the child's attitude and behavior. Positive communication between the students and others can often be facilitated by the counselors and students participating in a variety of role-playing situations. Role-playing can also afford students the opportunity to experience how others might feel about what they have said and done. Impulsivity, frequently a major problem, can be eased by teaching children problem-solving. Past situations which may have resulted in their getting into trouble, losing privileges or other undesirable consequences, can be analyzed objectively, while the possible outcomes of alternative actions are discussed relative to the way the student would have preferred these situations to have been resolved.

Counselors are obligated to protect students from unfair or discriminatory treatment and, thus, assure their being granted equal access to a variety of suitable settings. Although many

professionals may not fully comprehend the finer points of laws relating to these children, generally, what is legal is appropriate and just a matter of good common sense. For example, a counselor would not want to be put into the position of advocating a classroom teacher use a behavior plan or behavior modification techniques as means of controlling the verbal and motor tics exhibited by a student with Tourette's Syndrome. Similarly, none would want to demand an afflicted child wear a device while at school to muffle the sounds of his verbalizations. Each of the preceding would, not only constitute a clear violation of the child's rights, but could, additionally, be further construed as punitive or abusive.

Students with Tourette's Syndrome and/or Attention Deficit Hyperactivity Disorder are in need of a great deal of assistance. Although at times counseling these children can be frustrating, observing students who were once "loners" or poor achievers assume productive roles within society is seen as well worth the effort.

*Joan Murphy, LPC

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**SUGGESTIONS FOR TEACHERS OF STUDENTS
WITH TOURETTE'S SYNDROME AND ADHD**

Janene Delany, M.Ed.
Jan Nelson*

- I. Organizational Skills
 1. Prioritize assignments
 2. Help him to use assignment notebook on a daily basis
 3. Ask that notes be kept in a separate notebook
- II. Learning Strategies
 1. Practice using various textbook sections before assigning work
 2. Provide an example of the way you would like the work done
- III. Classroom Adjustment/Behavior Management
 1. Reduce distractions by seating students in front of room.
 2. Establish regular classroom routines
 3. Maintain eye contact while giving clear, concise oral directions; limit the number of steps to be taken. Check for comprehension
 4. Provide partially completed outlines to guide note taking
 5. Make allowances for freedom of physical movement to alleviate restlessness
 6. Peer tutor, making carbon copies, use of tape recorder or allowing student use of small, silent, portable typewriter in class
 7. When changing activities, expect student may need more time to adjust

8. Activities should be short (15-20 minutes), low to moderate in level of frustration, with a variety of types of activities; "hands on"/high student involvement
9. "Distract" to cause cessation of behaviors
10. Establish open, frequent communication with student's family

IV. Modification in Test Taking

1. Model skills or sample problems immediately before administering tests
2. Reduce the number of test items per section and/or on each page
3. Reduce the number of multiple choice alternatives
4. Underline key words in test directions and test questions
5. Provide additional spacing between different test sections requiring different response formats
6. Administer tests, if need be, orally
Tape or write student responses
7. Abolish time limits. Administer tests in sections

*Janene Delany, M.Ed.
Jan Nelson

LIMIT SETTING WITH STUDENTS

Tom Waters, Ph.D.*

Tourette Syndrome is a neurological, multiple tic disorder that often starts in early childhood, before youngsters enter school. The nature of the classroom setting, however, with its inherent restrictions and demands can turn what is already a difficult problem, into a nightmarish situation, if not handled skillfully. MOST CHILDREN WITH TOURETTE'S SYNDROME LEARN BEST IN A MODERATELY STRUCTURED CLASSROOM. Something between an open classroom and a more rigid traditional classroom is recommended. Youngsters need the guidance of clearly articulated directions from teachers, as well as the opportunity for independent movement. Educational plans for TS students should include provisions for a refuge area, i.e. guidance office, resource room, etc. These children need to have a private area in which they can retreat, where expression of the tics will not be noticed, should their symptoms become intense.

Against this "release with control" school environment for children with Tourette's, the following points for "setting limits" are offered, which may be applied to dealing with numerous other "special" students at school and elsewhere.

1. Give short, clear, direct instructions to promote understanding of expectations.
2. Be kind, but firm, doing what you say you will do. Avoid making threats.
3. Expect compliance. Do not say "try" but anticipate the student will do as he is told, and if there are problems these can be discussed. Give choices carefully.

4. Be consistent, kindly enforcing a predictable schedule.
5. Use effective contingencies that have demonstrated reinforcement value.
6. Offer early warning of time limits, avoid abrupt transitions and prepare students to anticipate stressful experience such as tests and scores.
7. "Accentuate the positive and eliminate the negative" as frequently as possible.
8. Provide immediate feedback and distributed practice.
9. Foster feelings of self-esteem and explicitly model effective coping and personal-social adaptive skills.
10. Facilitate and encourage clear, open, direct, and specific communication between teacher, parent, and medical personnel on behalf of the youngster so that efforts are coordinated and not at cross purposes.

*Tom Waters, Ph.D.
Clinical Psychologist

**ADAPTING ATHLETIC PROGRAMS
FOR TEAM ACCEPTANCE**

Coach Alvin Stewart*

All physically adept students with a particular propensity towards sports, should be encouraged to participate in school athletic programs.

Students who perceive themselves as "different" are more inclined to lack self-confidence and be expected to need at least some support in joining a sport's activity. Prior to the beginning of the season, either the parents or the student (depending upon the age of the student) should contact the coach to discuss any anticipated problem areas.

Acceptance of the student by the team can best be accomplished through mutual understanding, a shared responsibility, and a commitment by all to maintain open channels of communication. A key factor in fostering acceptance and understanding by team members for any individual with a disability is education. The tourettor and his teammates need to be completely familiar with the disorder. Only with such knowledge will they be able to accept and adequately deal with situations which may arise.

In order for team members to understand the nature and variety of symptoms, the coach might wish to bring in a consultant or specialist to meet with the group. The speaker should emphasize that the various manifestations of Tourette's are involuntary and vary in severity. Adequate time should be allotted for an exchange of questions and answers.

Expectations should be realistic. All teammates will not respond in the same manner, nor

will all accept the new player in the same way. The coach can assist the athlete with Tourette's to acquire a positive mental attitude and to accept each day as a challenge. The student must assume the responsibility for not taking advantage of any special concessions given. Coaches and team members are quick to notice when special considerations are requested on a routine basis, especially if they occur during tedious practices or when activities scheduled are inconvenient.

A student with Tourette's can, with the support of his coach, others in the athletic program and a healthy attitude, become a vital, contributing member of any team, both on and off the playing field.

Suggestions for coaches of athletic programs

1. Be genuine.
2. Provide the athlete with an advanced copy of the practice schedule for each day.
3. Assign a peer tutor to the student to assist him in learning the game strategy (a willing teammate, not a forced situation).
4. Allow the athlete periods of adjustment should severe problems arise (causing a distraction to the rest of the team).
5. Provide the student with a game schedule which includes departure times, as soon as possible.
6. Offer continuous encouragement and praise when deserving.
7. Hold tutorial sessions with the athlete in private.
8. Convey a warm, non-judgmental attitude, and invite the student to discuss all problems which might arise.

*Coach Alvin Stewart
Special Education Teacher
Capitol High School

WHAT AND HOW A SPECIAL EDUCATION PROGRAM CAN HELP YOUR CHILD

Pat Cooper, Ph.D.*

Education for all children, including those with Tourette's Syndrome, should serve to provide a conduit for each child's academic, as well as, mental and emotional growth. When that growth is hampered or prevented, at the least, attention should be given to the child's situation, and in some cases "special" educational strategies should be utilized. Keep in mind that "special" educational strategies can include many efforts other than the classic special education self-contained and resource classes.

Many state laws and regulations require that a broad array of services should be provided to students with learning or emotional problems. Among these services are the School Building Level Committee (SBLC) at each school, local school assessment teachers, social workers, school psychologists, and formal intervention procedures put together by local system pupil appraisal personnel. None of these services requires an evaluation or label for the student. Success, many times, can be achieved for the child outside of the traditional special education system. Those alternatives should be pursued. Parents should ask, pester, demand these first-line services from local school system professionals!

There are times when more serious and extensive special education services are required. These should be clearly defined by formal evaluation results which are discussed extensively with the parents. If formal special education services are needed, then parents must not only demand educational help and support, but there must

be assurance that certain principles are adhered to by the school system. These Principles are carved out of the previously mentioned laws and regulations.

Principle 1: Children should only be removed from the regular education environment (school or classroom) if services that are deemed appropriate and needed cannot be supplied in that setting. Although such a situation seldom exists special classrooms are sometimes needed. Special segregated schools, however, rarely are. There must be a strong, compelling reason for "separate" schooling.

Principle 2: To the maximum extent possible, disabled children must be educated with children who are not disabled.

Principle 3: Unless there are educationally compelling reasons (not financial or ease of effort), exceptional children should attend the school closest to home...the school they would normally attend.

Principle 4: Disabled children must have available to them all services and educational programs available to non-impaired students.

Parents should ask that specific goals be included in the IEP which will help their child reach his/her potential. Special education can be beneficial, if monitored by parents and accountability is expected.

Parents of children with disabilities have rights, and their children have rights. Parents must, however, know what those rights are in order to avail themselves of these rights.

*Pat Cooper, Ph.D.
Executive Director
National School Health Education Coalition

MEETING THE NEEDS OF TS/ADHD STUDENTS
IN THE SPECIAL EDUCATION CLASSROOM

Lorraine M. Kelley, M.Ed.*

When students are placed in special education classes, many parents expect this will be the panacea to their problems. While this is not necessarily true, special education teachers and classes can do much to address the needs of these students.

During the initial entry period, the teacher usually takes particular care to help the student adjust by familiarizing him with general classroom procedures. Instructors are aware that a majority of students disabled by TS/ADHD experience feelings of low self-esteem and are particularly sensitive to peer pressure.

These children must also be helped to deal with difficulties typically encountered as a result of their placement in special education. Commonly asked questions relate to why the students were placed in these classes, how they can explain it to their friends, and how the remediation of their deficits in special education now will help them in their future lives.

The primary (IEP) teacher must then begin to deal with the problem of addressing the educational needs of the child. The lower pupil-teacher ratio within the special education setting affords the teacher greater opportunity to understand how the child's particular difficulties may be affecting him. Individualized instruction, possible in this lower stress setting, also allows the student more freedom to learn and gain self-confidence. Children with ADHD characteristically lack patience. They have difficulty looking ahead and envisioning the possible consequences of their

actions. These students are encouraged to cope with "real life" problem situations. The added time the teacher can spend getting to know each student also tends to help foster the development of a nurturing, supportive environment. Many of these students view their instructors as allies in whom they can confide. Although a student may not be able to read as well as others, he will rarely have trouble "reading" the concern for his welfare by these instructors.

Data in the student's evaluation assists the teacher in determining his academic levels, strengths and various needs. Information in the evaluation may also suggest the student's learning style. Special education instructors must meet with other teachers in regular education. During these meetings, information about the student's progress and difficulties is exchanged. Teaching strategies are often evaluated in reference to their effectiveness in helping the student to meet the educational goals and objectives stated on his Individualized Education Program (IEP). Normally a multi-modal approach, utilizing a variety of senses including auditory, kinesthetic, and tactile, is employed with all levels of students in all types of settings.

Learning strategies are utilized to include techniques for listening, following directions, studying and test taking. Students are taught procedures to facilitate learning content and how to utilize library reference materials. Classes in social studies, literature, and some sciences may require more reading than do other classes. Students are taught to outline test materials, pick out main ideas, learn the definitions of highlighted or bold print words, etc.

These techniques are also applicable to achievement in math courses. Additionally, the students are given an opportunity to practice and relearn how to perform basic operations. A variety

of materials are employed to teach skills, such as the addition of fractions, multiplication and division of whole numbers, fractions, percents, and others. Computers, when available, although of value in reviewing vocabulary and spelling words are especially helpful in teaching math at all levels of difficulty.

Students attempting to acquire skills for independent living are provided with a wide variety of "hands on" experiences. They learn to fill out job application forms, Social Security cards, write checks, and complete bank withdrawal slips. These students are taught such basic tasks as how to read bus and train schedules, to follow recipes, and how to determine when TV movies will be shown.

Often, a diagnosis, alone, of either Tourette's Syndrome or Attention Deficit Hyperactivity Disorder, and identifying those difficulties as being related to a disorder, can do much to foster self-acceptance by affected individuals. Too often these students have been blamed for doing poorly academically, being told they were lazy, stupid, or just not trying hard enough. Parents of these children, also, do not remain unscathed, as frequently assumed guilty of poor parenting skills. Those disabled by TS or ADHD have many resources available to them in special education which can help them to learn and to become productive, independent members of society.

*Lorraine M. Kelley, M.Ed.

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**ALTERNATIVE PLACEMENTS:
MEETING THE CHILD'S INDIVIDUAL NEEDS**

Charles Nettles, M.Ed.*

Anyone involved with special education (parents, teachers, students, legislators, attorneys, the general public, etc.) should know that children who are eligible to receive services under Public Law 101-476 are to be provided a "free and appropriate education" in the least restrictive environment. This law was written to meet the INDIVIDUAL NEEDS OF EACH STUDENT, with the intent being that a program would be designed for EACH child eligible to receive special education services. One which would specifically meet that child's unique needs.

Most would likely agree that, if possible, each and every child should be educated in the regular classroom. Unfortunately, all children's needs cannot be met in the regular classroom. A model to be used as a guide to help educators in making decisions regarding possible placements was designed by Deno. The federal government's Office of Special Education and Rehabilitation Services currently uses an adapted version of Deno's model as a basis for placement categories to help in making decisions. The alternative setting is located near the bottom on this continuum.

The alternative setting is considered more restrictive and only a small percentage of children require this type of placement. The alternative setting could be a residential school or a special day school where children might attend the entire school day. In an alternative setting, they might receive vocational training, on the job training (unpaid and paid), academics, and the opportunity to participate in athletics. Here, they might learn to fit into a smaller community, while

preparing to move out into the world as a productive, self-sufficient, contributing member of society.

A variety of reasons might very well necessitate an alternative placement for a child/student. Following are some possibilities:

1. The student may refuse to attend school on a regular campus for a variety of reasons including:

never having had the opportunity to succeed,

having been made fun of constantly for being "special ed",

having experienced name calling such as "retarded", and "dummy",

not having been included in activities (academic, athletic, social),

having been laughed at or whispered about,

having no adult who was accepting of his differences. Only those who became upset when the student did not "fit in".

Students may easily have developed extremely low levels of self-esteem as a result of the above, and designing an alternative placement for some students may be the only way to keep them in school.

2. Students may have need of the smaller student/teacher ratio usually afforded in an alternative setting, as well as the opportunity to learn academically and

vocationally (depending on individual needs), while learning to function within an environment which is more accepting of individual differences.

3. Students may be older than those on a regular campus, since it may be necessary for some special education students to stay in school for a longer period of time than is required for diploma bound students. Understandably, they may feel out of place going to school with the younger students.
4. A program offered in an alternative setting might best meet the needs of the individual non-diploma bound student. Preparation for the world of work might appear more relevant to students and may more realistically meet their needs.
5. Students may have experienced difficulties with the law (many times as an indirect result of their disability) and an alternative placement may be a chance to get back on track.

Whatever the reason for placement, every child should have available to him, a program which will best meet his needs.

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*Charles Nettles
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SCHOOL TO WORK TRANSITION

Judith L. Goodstone, Ph.D.*

Transition is a term that has been used by people in many different fields. Recognizing that the problems associated with lack of systematic planning for adult life, the federal government included the transition concept in the Individuals with Disabilities Education Act (IDEA). The government further mandated that the schools provide transition services for all students (aged 16 and over) on the IEP. In addition, the transition services should include appropriate linkages to adult agencies.

In Special Education, transition means a coordinated set of activities which promotes movement from school to post-school activities. These activities are based on the student's needs, preferences, and interests, and they include instruction as well as community experiences and employment objectives.

In order to help families and schools promote good transition services, planning and communication must occur. A transition meeting is held annually to discuss desired adult outcomes. This means that the student, the family, the school personnel, and any other appropriate persons talk about the best possible future that the student could have. Then they discuss how the student could be helped to achieve the best and most independent lifestyle.

The discussion focuses on 11 target areas which should be planned for the future. These areas are: postsecondary education, employment, living arrangements, homemaking needs, income needs, community resources, recreation,

transportation needs, medical services, relationships, and legal needs.

Louisiana has mandated that all school systems complete a form called the Individualized Transition Plan (ITP). This form is to be filled in at the conclusion of a transition meeting and represents the agreement of the persons at the meeting. The ITP includes necessary action steps to help the student achieve independence in each of the target areas. The school steps will be those activities which are typically done in the school such as vocational education and job sampling. The family steps might include visiting a college or going to a meeting at Mental Health.

Thus, all persons who are involved in the life of a youth with disabilities discuss how to help that student live the most independent and typical lifestyle possible. Transition planning will differ for each student but should guide the schools and family to furnish the student with skills and competencies essential for adult living.

*Judith L Goodstone, Ph.D.

Louisiana Office of Special Educational Services

VOCATIONAL ASSESSMENT

James Brolin, C.V.E., L.R.C.*

Vocational/Career Assessment can and should be a unique meaningful experience for persons with Tourette's Syndrome. Done correctly, it will be a valuable tool in aiding the individual in making some very important life decisions, avoiding the frustrating waste of time and human potential, and aiding the person in becoming a productive, participating citizen.

Vocational Assessment cannot be accomplished simply by giving a test. The process of obtaining enough information about a person in order to help him/her make critical and informed career decisions is a complex procedure. Unfortunately, most people only receive a part of an assessment -- if any at all.

Vocational Assessment consists of a process which, 1) identifies the individual's vocational strengths and limitations, 2) identifies optimal vocational objectives, and 3) presents a plan for reaching those vocational objectives.

IDENTIFYING VOCATIONAL STRENGTHS AND LIMITATIONS.

This is the "information gathering" phase of vocational assessment. It is not a medical or psychological evaluation (although the vocational evaluator uses information from these assessments). It is an assessment of those strengths and weaknesses which are job related. Specifically, the evaluator must know the individual's functioning levels in educational achievement, physical capacities, abilities, interests and

needs. This includes a knowledge of the person's functional levels in :

Education:

- Reasoning
- Language
- Mathematics

Physical Capacities:

- Strength
- Lifting, Bending, Stooping
- Seeing, Hearing
- Use of limbs
- Handling

Abilities:

- Intelligence
- Verbal Aptitude
- Numerical Aptitude
- Spacial Ability
- Perceptual Ability
- Gross Motor Coordination
- Fine Motor Dexterity
- Color Discrimination

Interests:

- Artistic
- Scientific
- Plants and Animals
- Protective
- Mechanical
- Industrial
- Business Detail
- Selling
- Humanitarian
- Leading - Influencing
- Physical Performing

Needs:

- Dealing with Data, People, or Things
- Temperament
- Environment
- Work Situations

To gather this information, the vocational evaluator has at his/her disposal a great variety of tools, such as: standardized tests; vocational assessment instruments; interviews; and medical, school, and psychological reports.

IDENTIFYING OPTIMAL VOCATIONAL OBJECTIVES.

The second phase of vocational assessment involves the identification of possible vocational objectives. We know, for instance, that most people are capable of performing hundreds of jobs that exist in the labor force. But we also know that many people are dissatisfied with their employment or professions and have come to them by chance, not through planning. Research indicates, however, that job "satisfaction" comes through the matching of one's abilities and needs with the demands and rewards of the job.

The reason we have chosen to identify the areas of strengths and limitations listed above is to be able to MATCH this information to the world of work, and the best way to accomplish this is to compare the information we have on the individual to the job opportunities existing in the job market. The U.S. Department of Labor has done, and continues to do a thorough analysis of jobs that exist in the American labor force. The vocational evaluator can match the individual's profile to these jobs, identify the areas into which the individual can enter employment, and identify areas the individual can enter with specialized training, thus building a "career ladder" of possibilities for the individual.

You will notice that up to this point, we have not discussed Tourette's Syndrome specifically. This is because after we have matched the individual's vocational strengths and limitations to the world of work, it is then that we must look at the medical and psychological information. Should low stress occupations with absorbing

activities be given primary considerations? And should jobs dealing directly with people or customers be avoided? None of these questions can be answered with absolute certainty, but a careful reading of individual's medical and psychological information can give direction to the process of job matching.

DEVELOPING THE PLAN

No career/vocational plan can be developed without the active involvement of the evaluatee, and if the individual is a juvenile, the parents. At this point, the vocational evaluator presents possible job options, explains specific career options, and encourages the individual to make preliminary decisions, such as: Do you want to enter the labor force immediately? Are you willing to move or do you wish to remain in this location? Are you willing to continue your education? Are you interested in specialized training? And where, in five years, do you want your career to be? This plan is, and must be a team effort. When the individual is ready to begin making career decisions, it is the evaluator's responsibility to provide information about the individual and the world of work, offer options, and explain requirements. But it is the individual's responsibility to make the decisions.

The plan is, in effect, a road map showing where the individual is at the present time, his/her career destination, and the route or routes that can be taken to the destination.

And finally, we know that comprehensive vocational assessment is not easily available to persons with Tourette's Syndrome. But, with persistence, individuals and their advocates can receive this service through the State Vocational Rehabilitation Agency, Education Agency, or the private sector. We suggest that, when considering

a vocational assessment service or program, the following questions be asked:

1. What information will be obtained in the vocational assessment? Is it comprehensive? And does the information obtained through testing, interviews, and case reviews, relate to the real world of work?
2. Against what job criterion is the information being matched? Is the information on the individual being compared to a comprehensive job bank that contains jobs that have been thoroughly analyzed?
3. Will the assessment involve the evaluatee in the process? Are his/her interests, needs, and abilities considered?
4. And as a result of the vocational assessment, can a comprehensive career plan be designed with the individual making all decisions?

Vocational assessment can be such a valuable service to persons with Tourette's Syndrome, we can and should demand that it be done comprehensively and meaningfully.

*James Brolin, C.V.E; L.R.C
President, Green Square Associates

28.

**CAMPUS-BASED ASSISTANCE FOR STUDENTS
WITH LEARNING DISABILITIES AND/OR
ATTENTION DEFICIT DISORDER**

Rhonda Atkinson, Ph.D.
Tina Schultz, M.A.*

A learning disability is essentially a discrepancy between a student's potential and demonstrated ability. While many people think of a learning disability as a reading disorder, learning disabilities can be manifested as disorders in acquisition of information (input through listening or reading) and/or demonstration of learning (output through writing or speaking). Attention Deficit Disorder affects a student's ability to concentrate in a variety of activities that can involve input and/or output processes.

Part of the enigma which surrounds learning problems attributed to learning disabilities and/or Attention Deficit Disorder concerns the variation of characteristics which describe a particular student. These characteristics exist on a

continuum which ranges from very mild to extremely severe. All phases of academics may be affected, or only one or two areas may pose problems. For example, some students experience difficulty in processing foreign languages in which they must listen and respond to spoken information, although their English writing skills are unimpaired. Others have difficulty performing mathematical computations, although they possess the ability to solve verbal logic problems. Still other students require accommodations in all the classes they take.

Campus-based assistance for students with disabilities is legislatively mandated by Section 504 of the Rehabilitation Act of 1973. Under 504, the university is required to provide reasonable accommodations, and if accommodations are deemed appropriate, faculty are expected to comply upon written notification of the students under the auspices of the Office of Services for Students with Disabilities. However, it is the student's responsibility to notify faculty of and make arrangements for accommodations to be carried out. For example, a student might remind a professor that special testing arrangements are required prior to the date of the exam.

Students may apply for and receive accommodations at any point in their academic career, from orientation programs prior to enrollment in classes, through graduate school coursework. In general, students must meet the same admission requirements as other students; however, special consideration can be made for those students who self-identify and address their special circumstances during the admission process. In addition, admitted students with appropriate documentation are eligible for accommodations in taking placement tests prior to registration for classes.

In order to obtain services, students with documented disabilities must report to the Office of Services for Students with Disabilities in the Dean of Students' Office. The coordinator of the office then arranges for reasonable and appropriate academic accommodations based on the recommendations of the evaluator. In many cases, the authorization to provide accommodations can be completed at the time the student presents documentation. Implementation occurs as soon as the student notifies the faculty member. More than half of the students with disabilities at Louisiana State University receive services for learning disabilities and/or Attention Deficit Disorder.

To qualify for accommodations for a learning disability and/or Attention Deficit Disorder, a student must provide appropriate documentation from an outside evaluator. This documentation is required because the needs of students with disabilities and/or Attention Deficit Disorder are sometimes difficult to assess and require a variety of services. The evaluation must have been completed no more than three years prior to the time that services are requested. The evaluation should be performed by a certified professional, such as a licensed psychologist who has expertise in evaluating the learning problems of adults. At the very least, the assessment should include an intelligence test (e.g., the Stanford-Binet Intelligence Scale: Fourth Edition or the Wechsler Adult Intelligence Scale-Revised), an assessment of information processing such as the Bender Visual Motor Gestalt Test, and a measure of achievement (e.g., Wide Range Achievement Test-Revised or the Woodcock-Johnson Psycho-Education Battery, Part II-Tests of Achievement). The documentation should also provide a history of the student's background with emphasis on previous academic difficulties, medical issues, family history, and elementary/secondary accommodations. If appropriate, the examiner should also include a summary of recommended academic accommodations. As in other

disabilities, the university does not test or otherwise evaluate students for learning disabilities and/or Attention Deficit Disorder.

Accommodations for learning disabilities/Attention Deficit Disorder are quite varied depending on the recommendations of the evaluator. The university is responsible for hiring and paying individuals to be interpreters, scribes, notetakers or to provide other services necessary for parity in academic situations.

Course accommodations include priority registration, priority seating in class, taping of class lectures, notetakers, and extended time to complete assignments or courses. Devices which translate written text into voice output or which enlarge text are available for student use outside class. Computers are also available for word-processing, spell-checking, and other functions.

Testing accommodations include extended time on tests, changes in test format (e.g. excluding use of scan-tron code sheets, changing multiple choice questions to essay questions), credit for work shown, testing in separate rooms to allow students to concentrate without external distractions, spelling exclusions, provision of student-scribes to record verbal responses instead of requiring written responses.

In some cases, course substitutions (e.g., allowing a verbal logic course to substitute for algebra) are also valid accommodations providing that the original course is not essential to the pursuit of a particular major. For example, a verbal logic course would be an appropriate substitution for students pursuing a non-scientific/non-mathematical degree such as journalism or music. Such a substitution would not be appropriate for students majoring in a curricula which require mathematical expertise (e.g., engineering or physics).

In summary, the assessment for learning disabilities/Attention Deficit Disorder and the establishment of academic accommodations are critical to the academic success of these students in postsecondary education. The implementation of academic accommodations utilizes both the current disability documentation and the student's self-report of academic difficulties. Without appropriate academic accommodations and support services students with learning disabilities/Attention Deficit Disorder cannot compete equitably with their non-disabled peers.

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and

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Louisiana State University

SECTION V

LEGAL

CHAPTER

29. When your Child's Needs are Not Being Met
- - Administrative Agency Remedies and
Due Process
Joint Efforts of Members of ACED
30. Social Security Benefits
Hank des Bordes, J.D.
31. What Should Your Child Do If Stopped by
the Police?
Hank des Bordes, J.D.
32. Procedures at Family Court
Al Robelot, Jr.
Paulette Bordelon

**WHEN YOUR CHILD'S NEEDS ARE NOT BEING MET --
ADMINISTRATIVE AGENCY REMEDIES AND DUE PROCESS**

Joint efforts of Members of ACED*

INFORMAL RESOLUTION PROCEDURES

From time to time, parents may be dissatisfied with one or another aspect of their child's educational program. When dissatisfied, always first try to resolve differences with the school system in as informal a manner as possible.

The first course of action should be a phone call and/or a visit. At an informal meeting with the teacher and/or the principal, you can clearly and calmly explain the problem and, if possible, offer what you believe would be a solution to the problem. If school personnel agree with your position, you can follow up your phone call or meeting with a letter outlining the problem and reiterating the agreed-upon solution. If school personnel agree that there is a problem but offer a different solution, you may wish to consider the school's proposal. You may accept the school system's solution, accept it on a trial basis, or attempt to compromise with school personnel.

If attempts to resolve the problem at the school level do not work, you may next wish to contact the special education supervisor. Write a letter explaining why your child needs a particular service, attaching a statement from a professional if you have one, and requesting an IEP meeting for the purpose of amending the IEP. If, at the IEP meeting, the school system will not agree to the service, then you should write your request in the comment section of the IEP. If that does not work, you have the option of filing a complaint with Complaint Management (or with the Office of Civil

Rights if you suspect discriminatory conduct), requesting mediation or going due process.

COMPLAINT MANAGEMENT SYSTEM

If you feel your school district is violating the educational rights of your child or a number of students, you may consider filing a complaint with the State Department of Education (DOE). (In larger school districts there may be a designated Complaint Management Officer.) Your complaint should be in writing and should contain information, as specific as you can provide.

Under federal regulations, DOE must review, investigate, and resolve any complaints regarding a school district's special education program within sixty (60) calendar days. To ensure a thorough investigation, it is important that the person making the complaint remain in contact with DOE through the investigation period. It may be necessary to insist upon an opportunity to discuss your concerns in detail and to respond to the school system's version of events while the investigation is underway.

Any telephone conversations with investigators should be confirmed in writing. It is particularly important that the findings of the complaint investigation be in writing. If you receive a telephone call advising you of the outcome of the investigation, ask for a written decision, even if the investigator states the issue is "resolved" or "moot". DOE is required to make findings regarding whether violations have occurred and to provide technical assistance in order to get the school district to comply with the law.

Decisions of the Complaint Management Office may be appealed to the Federal Office of Special Education and Rehabilitative Services.

SECTION 504 COMPLAINTS

Under Section 504 of the Rehabilitation Act, "no qualified disabled person may be excluded from federally assisted programs or activities because a recipient's facilities are inaccessible or unusable". Section 504 applies to programming and physical accessibility; a student with a disability must have an equal opportunity to participate in his or her school's services and activities. If you believe that the school has violated Section 504, you may file a complaint with the State Department of Education Section 504 Coordinator, or with the United States Department of Education's Office for Civil Rights (OCR). It is important to remember that violations of IDEA are often also violations of Section 504.

The OCR complaint must be filed within 180 days from the date when the action about which you are complaining took place. It should state the basis on which you believe your child (or group of students) has been discriminated against, and provide a brief, but specific, description of conduct which you believe was discriminatory.

OCR will usually visit the school to conduct an investigation of your charges. You should also try to arrange to meet personally with the investigator. Be prepared to tell the investigator where he/she can obtain copies of your child's records. Give the investigator the names, addresses, and telephone numbers of any persons, such as attorneys, nurses, special education professionals, or other parents, who can support your complaint. You should be ready to support your complaint by presenting evidence concerning the kind of programs and services your student should be getting. Simply criticizing the program is not enough. Keep your allegations and charges factual.

Do not expect OCR to begin investigating your complaint immediately. However, OCR must send you a letter acknowledging receipt of your complaint and state when they will start to investigate your complaint. Call or write a short letter to check on the progress of the investigation. Also, keep OCR informed of any changes with respect to your child's program or evaluation. Always keep copies of any letters or other documents you sent or received from OCR.

There are some risks involved in filing a complaint with OCR. For example, once you file a complaint with OCR, you may have to wait until it has finished its investigation before you can file a lawsuit. However, most courts will not make you wait until the OCR investigation has ended. On the other hand, OCR may suspend its investigation if a due process hearing or lawsuit is pending.

MEDIATION

In situations where there appears to be a chance of resolving a dispute without a due process hearing the State Department of Education may provide a mediator. Mediation is available only if both you and the school district agree to it. A mediator, trained and selected by the Department of Education, will talk with you and school personnel, separately and together. Sometimes mediators prefer that lawyers not participate, but most of the time you will be allowed to have counsel with you at the mediation session.

An advantage of mediation is that it gives you one more chance to try to get your problem resolved without going through the time, trouble, expense, and stress of a due process hearing. If the law is clearly on your side or the school's side, the mediator might so advise you and the school officials. School personnel might accept such advice from a mediator, even if they do not agree with you. However, if agreement is not very

likely, mediation might simply turn out to delay a solution to your problem. You do not have the accept the mediator's proposed resolution. You always have the right to ask for a due process hearing, so if mediation appears unlikely to succeed, you do not have to go on indefinitely -- you can simply ask for a hearing.

If mediation is successful, an agreement is drawn up by the mediator and is signed by both you and the school officials. Both parties are honor bound to make a good faith effort to implement the agreement.

IMPARTIAL DUE PROCESS HEARING

A due process hearing may be requested by parents or a school system when a conflict arises concerning the identification, evaluation, educational placement of, or the provision of a free, appropriate education to, an exceptional child or a child suspected of being exceptional. The hearing is conducted by a impartial hearing officer who has been trained in special education law.

Due process hearings require a great deal of advance preparation, and usually involve expenditures of significant amounts of time and emotional energy. If unsuccessful at the hearing, parents must bear the costs of their expert witness(es) and attorney, unless they later prevail on appeal. Therefore, due process should be invoked only when less formal attempts to resolve problems have failed or are unavailable.

LEGAL REPRESENTATION

If a parent requests the information, or if a due process hearing is initiated, the school system must inform the parent of free or low-cost legal services available in the area. Due process hearings are usually fairly formal and involve

rules of evidence and procedures similar to those used in court proceedings. While it is not required that parents be represented by a lawyer or paralegal at a due process hearing, experience shows that those who are represented usually do better. Persons trained in legal procedure can assist in preparation of the evidence, can ensure that the facts and evidence are presented to the hearing office according to the formal rules, and can make any necessary objections and legal arguments for the record. If the hearing decision is appealed by either party, the reviewer will study the record made at the original hearing.

Because of the short time limits imposed once a hearing is requested, it is important to seek legal advice and representation **before** asking for a due process hearing. A legal representative may be able to assist in resolving problems by means other than a formal hearing, or may advise that particular concerns be documented and other preparations made before a hearing request is made. Attorneys whose clients win at due process hearings or on appeal can recover their fees from the school system. Thus, some attorneys may be able and willing to provide representation for a lower than usual fee (or for no fee) if the case is strong enough that they expect to recover their fees later.

REQUESTING A HEARING

The procedures for requesting a hearing and selecting a hearing officer, as well as the time lines for requesting a review of the hearing officer's decision and for filing an appeal in court, are determined by State law or written policy of the State Department of Education.

Ordinarily, to request a hearing, a parent should send a written request to the supervisor of special education for the school district. If a school system requests a hearing, it must provide

detailed notice to the parents. Each hearing and each review involving oral argument must be conducted at a time and place which is reasonably convenient to the parents and child involved.

RIGHTS AT THE HEARING

Parents involved in due process hearings must be given the following rights:

- * to bring their child;
- * to invite the public;
- * to bring a legal representative and/or another person who can provide assistance and support;
- * to present evidence and witnesses and to question school district witnesses;
- * to prevent the use of evidence that was not shared with them at least five working days before the hearing;
- * to receive a written record or tape recording of the hearing and
- * to receive a written copy of the hearing officer's decision.

DECISION OF THE HEARING OFFICER AND APPEAL RIGHTS

The hearing officer is supposed to issue a written decision within forty-five (45) calendar days of the time he/she was chosen unless there is a request and a good reason for an extension of time. The decision of the hearing officer is final unless appealed. If the due process hearing was conducted by the State Department of Education, an appeal is made by filing suit in state or federal court.

If the hearing is not conducted by the state, any party not satisfied with the decision of the hearing officer may appeal to the State Department of Education. The state review official (or panel) will review the hearing record and the evidence, and may seek additional evidence and ask for legal

argument from both sides if it wants more information.

The review official(s) shall reach a decision within thirty days after the receipt of a request for review, and may either affirm the hearing officer's decision, overrule it, or order a new hearing.

The state review decision is final unless a party files suit in state or federal court. The court will review the evidence and the record, ask for additional information and argument if needed, and decide if the hearing officer and/or state review decisions were correct under the law.

PLACEMENT DURING DUE PROCESS AND APPEALS

The placement in effect at the time of the request for due process must continue until the hearings and appeals are finished, including any court action that may follow the due process hearing. This is called "stay put". There are two exceptions to the "stay put" rule: First, during the hearings and appeals process, the placement can be changed with the consent of all parties. Second, either the parent or the school district may ask the court to overrule the "stay put" provision of the law. If the judge agrees with the party who wants the placement change, the judge can issue a preliminary injunction ordering a change of placement.

Due process can, indeed, be an expensive undertaking. Parents may have to retain experts to be witnesses, some of whom may require partial advance payment. If parents are unable to retain an attorney with either Legal Services or a protection and advocacy agency such as the Advocacy Center, they may have to make an advance payment to a private attorney in order to obtain representation. Depending on their work situation, parents may have to forfeit a day's pay. These

costs add up, and should be considered along with the time commitment and emotional strain of going due process. If a family prevails at the hearing stage and either the school does not appeal, or the school loses on appeal, the family is entitled to have reasonable costs reimbursed by the school system.

*Joint Effort by Members of
Advocacy Center for Elderly & Disabled (ACED)
210 O'Keefe Ave., Suite 700
New Orleans, LA 70112

National Association of Protection & Advocacy
Services
900 Second St., NE
Suite 211
Washington, DC 20002
(202) 408-9514

Note: ACED is listed in some cities under "Legal Clinics" and might be located in some areas under this heading. Local and state bar associations often have an Attorney Referral Service, and the Protection and Advocacy Agencies should be well known to such associations. Additionally, if a parent so requests, the school system must inform him/her of free or low-cost legal services available in the area.

SOCIAL SECURITY BENEFITS

Hank des Bordes*

There are two types of Social Security benefits available to the person with Tourette's Syndrome before that person reaches retirement age. They are:

1. Social Security Disability (SSDI) for persons who have worked and paid Social Security taxes. The amount of benefits depends on how much one has paid into the Social Security system, his present income (if any), and property owned. The Social Security Office will compute the amount of benefits to which a person may be entitled.
2. Supplemental Security Income (SSI) for persons who have never worked or have not worked long enough to qualify for Social Security Disability. Children with Tourette's may qualify for SSI if their parents have low incomes. The Social Security Office can determine if the person with Tourette's is eligible for SSI.

Social Security Regulation (20 CFR sec. 404.1505) states:

(a) The Law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you must have a severe impairment, which makes you unable

to do your previous work or any other substantial gainful activity which exists in the national economy. To determine whether you are able to do any other work, we consider your residual functional capacity and your age, education, and work experience. We will use this definition of disability if you are applying for a period of disability insurance benefits as a disabled worker, or child insurance benefits based on disability before age 22.

If the person with Tourette's meets the disability criteria and the income rules, he or a parent should go to the local Social Security Office and file a claim for SSDI or SSI benefits. Since Tourette syndrome is not a well-known medical disorder, one must be prepared to explain to the Social Security clerk how Tourette's is disabling. The individual bears the burden to prove his disability.

Once a claim form has been submitted, the person's doctor will be sent a questionnaire by the Social Security Administration and will be asked to describe the disability. It is crucial that the doctor explains the disability in detail. The doctor should assume that the Social Security clerk has no knowledge of Tourette's syndrome. The doctor should explain the disorder, its effects, its severity, the individual's specific treatment and prognosis.

If Social Security denies the initial application, one needs to review his file and apply for a "Reconsideration". If upon review, one finds out that his file is incomplete, he should obtain all the documentation needed to complete the file. If the doctor did not describe the disability in sufficient detail, he should visit the doctor and ask him to submit a more detailed report to the Social Security Administration.

At the beginning of the "Reconsideration" stage one should also consult with an attorney knowledgeable in Social Security Law. The local Bar Association Referral Service lists the names of attorneys who handle Social Security cases. One should not be afraid to consult an attorney because he can not afford it. The attorney's fee is collectible out of the back payments due if the attorney wins the case on reconsideration or appeal.

If the "Reconsideration" is denied, one has the right to appeal that decision to a Social Security Administrative Law Judge. One definitely needs to consult with an attorney prior to filing the appeal. At the Appeal stage, the claimant will meet face to face with the Administrative Law Judge and will have the opportunity to describe the situation in detail.

If Social Security grants benefits, one needs to be aware that the case will be reviewed periodically. Therefore, the individual should read the Social Security literature concerning reviews and the literature concerning the right to return to work. In many cases the Social Security Administration will allow one to return to work on a trial basis, and although the benefits will be reduced, they will not necessarily be terminated, for the trial period.

It is also important to know that Social Security Laws do change. For information about an individual's rights, contact your local Social Security Office or an attorney.

*Hank Des Bordes, Attorney

WHAT SHOULD YOUR CHILD DO IF STOPPED BY THE POLICE?

Hank des Bordes*

The spokesmen for both the Louisiana State Police and the Baton Rouge City Police Department were asked, "What should a person with Tourette's Syndrome do if stopped by the police?" Both policemen had heard of Tourette's and they suggested that such persons carry a card with them stating:

I HAVE A MEDICAL CONDITION, I have Tourette's Syndrome, a medical condition that can cause involuntary verbal statements.

For verification, please contact:

My relative: (name)	Telephone No.
My physician:(name)	Telephone No.

It is suggested that the "I HAVE A MEDICAL CONDITION" words be printed in red.

When a police officer asks for a driver's license or other ID, the individual should be instructed to give the medical condition card to the officer with the driver's license. While the police officer might not know what Tourette's is, he or she will be alerted to the fact that the individual has a medical condition, and hopefully, the officer will handle the situation in an appropriate manner.

If a person is taken into custody by the police, when a parent or guardian is finally contacted, he/she should calmly explain the child's medical condition to the officer. One should request the officer to contact the person's physician for verification. If that doesn't work, a lawyer should be contacted.

*Hank des Bordes, Attorney at Law

PROCEDURES AT FAMILY COURT

Al Robelot Jr.*
Paulette Bordelon*

Editor's Note: The following article describes procedures followed at the Police Detention Center at Baton Rouge, Louisiana. As many areas do not have juvenile centers or have facilities with entirely different procedures, the value of this material to the majority of the readers was debatable. The decision to include the article was made upon consideration that, despite lacking applicability in all cases, information contained in the article still provided an example of the types of procedures which could be anticipated should a child be incarcerated.

If your child is charged with an offense and not released into the parent's custody, he will be placed in the City Police Detention Center which is located at the Family Court Center. The police do a pretty good job running this Center. One knows his/her child is safe, well fed and is not out at all hours running the streets. As a bonus, the child will not enjoy his stay there. He will not be able to go to the refrigerator at midnight, monopolize the phone, talk to his girlfriend, and he will have to attend school. He will follow a regimented schedule, even taking into consideration meals and recreation, he will still have plenty of time with which to re-evaluate his priorities.

The child will have a detention hearing at the next court date (Mondays, Wednesdays and Fridays are court days). He must be represented by an attorney at this hearing. If his attorney cannot be present, the judge may appoint the public defender (the parent may want to call an intake officer, prior to this hearing to discuss this representation). The purpose of this hearing is to determine if there is sufficient cause to keep the child in Detention, and to set the type and amount of bond.

If the child remains in Detention, an appearance hearing (arraignment) will be set in seven days, at which time he will enter a plea. If he is released from Detention at his detention hearing, the appearance will be scheduled by the District Attorney at a later date. As a general rule, the hearings progress at a much slower rate if the child is not in Detention.

The next hearing is the adjudicatory hearing (trial), presuming the child entered a not-guilty plea. If he pled guilty at the appearance, the matter is set for disposition (sentencing). If, at the adjudicatory hearing, the child is found innocent of the charges, the matter is dropped. If he is found guilty, or changes his original plea and admits guilt, he is adjudicated, or determined to be "delinquent." The matter is set for disposition. At this point, a probation officer is assigned to the case. The officer will prepare a report based on interviews with the child, family, and other sources. This report will conclude with a recommendation that is taken into consideration, by the judge before imposing the sentence.

During the initial contact with the legal system, it is important to inform all involved personnel (policemen, detention staff, etc.) that your child has Tourette's Syndrome, as well as mentioning the ways the disorder manifests itself in your child's case. One should be sure to talk with the intake staff at Family Court about this also. They will want to be familiar with Tourette's so they might assist you in all phases of court procedure. They can also answer questions about such things as hearing dates, possible dispositions, and matters concerning counseling and community resources.

*Al Robelot Jr.
Paulette Bordelon

SECTION VI

AGENCIES and SUPPORT GROUPS

CHAPTER

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VOCATIONAL REHABILITATION

Claire Hymel*

Accomplished through a planned sequence of individualized services designed to assist individuals with disabilities reach a vocational goal, vocational rehabilitation is an intervention process whereby persons with disabilities move from a position of dependency in their community to positions of self-reliance and independence in a community of their choice.

Eligibility for vocational rehabilitation services is dependent upon an individual meeting the following criteria:

1. An individual must have a physical and/or mental disability which for the individual constitutes or results in a substantial limitation to employment; and
2. There must be a reasonable expectation that vocational rehabilitation services will benefit the individual in terms of employment.

Vocational rehabilitation services are delivered on the basis of an Individualized Written Rehabilitation Program that has been developed by both the rehabilitation counselor and the client. This program plan (IWRP) combines the counselor's professional guidance with the needs and desires of the client and is developed after a thorough assessment and evaluation of rehabilitation potential and determination of the nature and scope of services needed for the individual to reach a vocational goal. While vocational rehabilitation services may vary from state-to-state, it is within the scope of federal regulations for Agencies to provide the following services:

1. Evaluation of rehabilitation potential;
2. Counseling and guidance;
3. Physical and/or mental restoration;
4. Vocational and other training services;
5. Telecommunications, sensory, and other technological aids and devices;
6. Occupational tools and equipment; and
7. Placement in suitable employment.

While vocational rehabilitation agencies have no age requirement, one's eligibility is dependent upon the services benefitting the person "in terms of employability." Therefore, application for services should be made at the time an individual reaches or nears the minimum age of legal employment. High school students with disabilities should make application for vocational rehabilitation services prior to their exiting the school system, as they may benefit from services designed to help the transition from school to work.

Vocational Rehabilitation Agencies are located in all 50 States, American Samoa, Puerto Rico, and Guam. To apply for services, one must be present in the state/territory. Agencies are generally located in Human Services Departments, Education Departments, Labor Departments, or Social Services Departments.

*Claire Hymel
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REFERENCES

- Emener, W.G. (1991), An empowerment philosophy for rehabilitation in the 20th Century, Journal of Rehabilitation, 57,7.

ADVOCACY SERVICES

ACED*

The Programs for Persons with Developmental Disabilities Act (DD Act) mandates that the Governor of every state designate an agency to provide protection and advocacy services for persons with developmental disabilities. These services are funded by the U.S. Department of Health and Human Services. Administration on Developmental Disabilities. Under the DD Act, persons eligible for services are those with a severe, chronic disability which:

- began before age 22,
- is attributable to a mental or physical impairment or combination of both, and
- results in substantial functional limitation in three major life activities, such as language, learning, mobility, self-care, self-direction, independent living, or economic self-sufficiency.

Parents are encouraged to contact the protection and advocacy agency (P&A) in their state for assistance. In addition to providing information and educational materials to assist parents to advocate more effectively for their children, many P&A's have identified special education issues as a priority area for representation. P&A's should also have information on disability education and support groups in the state, through which parents may learn about successful advocacy strategies of other families.

ACED is listed in some cities under "Legal Clinics" and might be located in some areas under this heading. Local and state bar associations

often have an Attorney Referral Service, and the Protection and Advocacy Agencies should be well known to such associations. Additionally, if a parent so requests, the school system must inform him/her of free or low-cost legal services available in the area.

CONTACT:

National Association of Protection & Advocacy
Systems
900 Second Street N.E.
Suite 211
Washington, DC 20002
(202) 408-9514

Joint Effort of Members of ACED (Advocacy Center
for the Elderly and Disabled)
2100 O'Keefe Ave.
Suite 700
New Orleans, LA 70112

NICHCY

The National Information Center for Children and Youth with Disabilities (NICHCY) provides free information to assist parents, educators, caregivers, advocates and others in helping children and youth with disabilities become participating members of the community. NICHCY operates as a national clearinghouse through the Clearinghouse for the Disabled Program authorized by Section 633 of Part D of the Education of the Handicapped Act (20 U.S.C.), as amended by Public Law 90-457.

Single copies of NICHCY materials are FREE. Permission to duplicate NICHCY materials is not required. In fact, you are encouraged to duplicate so long as credit is given to NICHCY as the source of the material.

Their materials can be broken down into several categories. GENERAL RESOURCE are in the GR series. NEWS DIGESTS are covered in the ND series. TRANSITION SUMMARY is in the TS series. DISABILITY FACT SHEETS are in the FS series. MATERIALS FOR PARENTS is in the PA series. There is also the EASY-TO-READ or ER series, and the LEGAL INFORMATION or LG series.

NICHCY can be reached by mail at P.O. Box 1492, Washington, DC 20013. Their local number is (202) 884-8200, and their nation-wide toll free number is, (800) 999-5599.

NATIONAL RESOURCES

1. ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660; (800) 328-0272
2. HEATH Resource Center (National Clearinghouse on Postsecondary Education for Individuals with Disabilities)
One Dupont Circle, N.W., Suite 800
Washington, DC 20036-1193
(202) 939-9320; (800) 544-3284 (Voice/TT)
3. National Clearinghouse for Professions in Special Education
Council for Exceptional Children
1290 Association Drive
Reston, VA 22091-1589
(703) 264-9476
4. National Health Information Center
P.O. Box 1133
Washington, DC 20013-1133
(301) 565-4167
(800) 336-4797
5. National Maternal and Child Health Clearinghouse
8201 Greensboro Dr., Suite 600
McLean, VA 22102
(703) 821-8955 Ext. 254 or 265
Publications available in Spanish
6. National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284
(800) 346-2742 (Voice/TT)
Spanish speaker on staff

PARENT TRAINING AND INFORMATION CENTERS
FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS

Debbie Braud*

The Individuals with Disabilities Education Act (IDEA), the federal special education law, establishes a grant program to support parent training and information centers to meet the needs of parents of children with disabilities. As specified in the law, the purpose of these programs is to enable parents to participate more effectively with professionals in meeting the educational needs of these children.

This section of law also requires a technical assistance and coordination component, which is implemented by the TAPP Project. Technical Assistance for Parent Programs (TAPP) is a system of peer support, allowing established, experienced parent centers and new centers to learn from each other and from other experts.

Delivery of technical assistance is arranged through four TAPP Regional Centers: PACER Center in the Midwest Region, Parent Information Center in the Northeast Region, Association for Retarded Citizens of Georgia in the South Region, and Washington State PAVE in the West Region.

At present the Parent Training and Information Program has at least one funded center in each state. In 1991 the total number of PTIs has reached 60. Most centers are staffed by parents of children with disabilities, and offer assistance through free workshops, parent to parent support, education of public laws, and individual assistance.

For more information about TAPP and the name and phone number of the PTI in a specific state, write or call: TAPP Project, Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston, Massachusetts 02116 (617) 482-2915.

*Debbie Braud, Director
Families Helping Families of GNO/Project PROMPT
Metairie, Louisiana

37.

THE OBSESSIVE COMPULSIVE FOUNDATION
(The O.C. Foundation)

OCD - - THERE IS NOW HELP

James W. Broatch, MSW*

The Obsessive Compulsive (OC) Foundation was started by people with the Disorder (OCD). They had all been treated at the Yale OCD Clinic under the direction of Wayne Goodman, M.D. The primary objective in beginning the Foundation was to inform both individuals with OCD and mental health care professionals that the Disorder was a treatable disease.

The Foundation's first project in 1987 involved having "20/20" air a segment on the recent advances in the diagnosis and treatment of OCD. The "20/20" segment brought news of new treatment to thousands of individuals who had been suffering in silence.

In the seven years since its inception, the Foundation has grown from a nucleus of twelve members meeting in the nurses' lounge at the OCD

Clinic to a national organization of more than 7,700. The OC Foundation has a Scientific Advisory Board consisting of some of the most notable researchers and clinicians in the field and has helped to set up over 250 support groups throughout the country. It has affiliated chapters in Pennsylvania, Minnesota and Rhode Island, and a fourth is now being set up in Houston, Texas.

The Foundation provides pamphlets and video tapes on various OCD related topics. Six times a year it publishes a newsletter for members, which contains articles on Obsessive Compulsive Disorder treatment and research. The Foundation also publishes a quarterly "Check It Out", a newsletter for OCD support leaders. "Check It Out" provides features on different support group formats, tips for leaders, highlights Foundation initiatives, and promotes sharing among groups and legislative action. The Foundation is producing a video about a child with OCD, entitled "The Touching Tree" which will be released in January 1993. In order to maximize its viewing, research is being conducted as to the various distribution options. During the last few years, the OC group has additionally cosponsored a number of seminars on the diagnosis and integrated treatment of OCD and related disorders. A continuation of this regional seminar format is planned.

In 1991, the Foundation hired a fund raising consultant firm to conduct a campaign feasibility study. The objective of the study was to determine whether OC possessed the capacity to raise three million dollars for ongoing operations, which was to include an increase in public and professional education and the establishment of an OCF research fund. The findings were mixed. Although the Foundation's image and services were considered to be excellent, the OCF was relatively unknown outside of its immediate community. In order to remediate this, the consultant's recommendations are currently being implemented.

Another important Foundation initiative is its ongoing advocacy with other mental health organizations that equitable mental health care benefits must be included in any health care reform legislation passed by Congress.

The most important priority of the Foundation will continue to be to provide information and support to individuals with OCD, their families, and service providers within the mental health community. It is hoped that the release of "The Touching Tree" will increase the public's awareness of OCD in children and help the Foundation to expand its viability and impact on a national level.

*James W. Broatch, MSW
Executive Director
OC Foundation

TS/ADD/ADHD AND SUPPORT GROUPS

John B. Kent, Jr.*

The purpose of support groups is to give aid and comfort to the people and families with TS/ADD/ADHD. These groups also provide information about these disorders to those affected as well as to the public. By joining a support group you have the opportunity to meet with others with similar problems, and to share those things you do that are working, as well as to find out about things that don't seem to be working well. You get to meet face to face others and to know that you are not alone in the world with this problem that is making such a mess of your life.

Unfortunately, not every community has a support group. Some communities may be of such a small size that forming a support group of much magnitude will be very difficult. In other communities it might well be that no one has become concerned enough to try to form a group. However, in every state there are support group structures. Some of these are independent and some are affiliated with one of the national groups, such as the TSA (Tourette Syndrome Association), ADDA (Attention Deficit Disorder Association), or Ch.A.D.D. (Children with Attention Deficit Disorder). Some of these affiliated chapters may encompass most of a state. Simply by becoming a dues paying member of the national organization, you become a member of the state or local chapter nearest you.

Obviously, there are limitations as to how much help you might receive from a support group that is so far from your home that you might never find yourself attending meetings. Nevertheless, simply by receiving the national newsletter, you will be a better informed person, and you will have access to information to which others, who have not taken the trouble to join, will not be aware.

Forming a support group in any area need not be impossible. However, it might be lonely meeting with the same three or four people all of the time and this can be discouraging. There are, though, groups of this small size which do valuable work for their members and others in the community. After all, in a small community with 5,000 children in the local schools there could be 250 ADD students and perhaps 25 to 50 TS students. Many of these will be "invisible" because they have never been diagnosed and their parents do not have a clue as to their problem. The smaller the community, the more important the support group will be, since smaller communities often lack the resources of larger communities.

Dealing with the local school system may be one of the major problems parents of one of these children will face. It is, therefore, very important that there be local support groups, so that school personnel can be made aware of the problems facing these children and family members. By better informing the teaching community, the schools can do a better job of educating ADD and TS students and have less trouble with them.

Every support group faces several similar problems. One of the primary problems will always be funding. If the group is to publish a newsletter, money will be needed. The cost for a low volume newsletter can start at about \$.40 for a single sheet, including postage. Once a group can qualify for non-profit status and get a bulk mailing permit, the cost for a single sheet

newsletter can go down to about \$.20. If the cost of duplication can be donated, then the primary cost can go down to about \$.10 for mailing either a one, two, or three sheet newsletter.

Publishing a newsletter, which is more than just a call of the meeting, can be one of the most valuable things a local support group does. This can be sent out to a wide range of caregivers in the community to help inform them about TS and ADD children. This might include neurologists, pediatricians, psychologists, psychiatrists, social workers, both public and private educators, and day care center personnel. Education is one of the key things any support group should do. The addition of these caregivers' names to the mailing list can help meet the minimum post office requirement for bulk mailing at reduced costs.

Another major problem every support group faces is maintaining continuing leadership. After all, it is one thing to be dedicated while your child is in school, but once the child graduates, most parents tend to go on to another stage in their lives, which doesn't always include being involved in support groups. This, then indicates the need for constant renewal of dedicated leadership to take up the job of keeping the group going. Burn-out is a never ending problem.

The professional community can also be of assistance in helping direct people to support groups. The neurologist or psychologist who has diagnosed the disorder, as well as the social worker or teachers in the school system, will often recommend that the child's parents make contact with these groups.

In order to have as much outreach as possible, it is important for local support groups to seek out free sources of publicity. Many newspapers have local monthly or weekly calendars of events and meetings. There are also many weekly or monthly free publications that publish calendars of events at no charge. Someone in the group needs to be in charge of keeping this information current and available to these publications in time to meet their particular deadlines. There also may be state agencies which provide information about groups for the disabled. Sometimes the local library keeps lists of local groups. Since most support groups are listed with the address and telephone of their current leader, it is important that this information be kept up-to-date with all of the publications or agencies with which they are listed. If a group can not be reached, its ability to attract membership and attendance will be limited.

Because the TS community is so much smaller than the ADD community, it might be possible for the TS group to unite with an ADD group to hold meetings, share expenses, and help with the leadership chores. After all, these two groups of people have many things in common, and a working relationship between the two can be beneficial to one and all.

There are both advantages and disadvantages of the local group being affiliated with a national group, but generally, the advantages out-weigh the disadvantages. The national group will add stability to the local group and help direct people to the group. Failure of leadership at the local level is going to be disastrous regardless of a national affiliation though. No matter what the choice of affiliation, the objective of the local group should always be to promote the welfare of the local membership.

If your child has TS. or ADD, perhaps your community is just waiting for you to start a support group. Don't be bashful. Step right up. Start by making inquiries of your school's staff about who might have an interest in forming such a group. Check with your own local caregiver about directing others to you who might have an interest. Most professionals will not provide the names of their patients, but they may be glad to make a referral on your behalf. You might also ask your local caregiver about directly helping start the group of other professionals who might have such an interest or be willing to serve in an advisory capacity. Until you ask, you will never know who might be willing to assist you in forming and running a new support group. The impetus for starting a local group does not have to originate with a parent. It can just as well begin with a caring professional or educator who recognizes the need.

*John B. Kent, Jr.
Business Manager
Baton Rouge Tourette's Support Group

THE TOURETTE SYNDROME ASSOCIATION (TSA)

The national TSA is an international voluntary non-profit organization dedicated to the prevention, control and cure of Tourette syndrome.

The Association's major programs include:

- * Services for clients, their families and interested professionals;
- * Stimulation and direct support of research into the causes of TS and new treatments;
- * Public and professional education to foster early diagnosis and appropriate treatment

TSA is the major source worldwide of current information about the disorder. An extensive selection of publications and audiovisuals are available. A quarterly newsletter keeps physicians and lay members informed about current treatments, research programs, scientific discoveries and TSA national/chapter activities.

A Catalog of Publications and Films can be obtained from:

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361
(718) 224-2999
(800) 237-0717
Fax (718) 279-9596

Ch.A.D.D.

According to the Ch.A.D.D. Chapter Formation Manual: Ch.A.D.D., Children with Attention Deficit Disorder, was started in Plantation, Florida in 1987 by a group of parents of children with Attention Deficit Disorders and by local professionals who had an interest in working with the children. Because there was a noticeable lack of current information within the lay community about Attention Deficit Disorders and few available forums by which parents could communicate with one another, an organization designed for parents seemed to be needed. The founders were surprised to see just how great this need was. They began by holding monthly parent meetings which served as both a support group and as a setting for informational programs about Attention Deficit Disorders. It did not take long before parents in neighboring communities and throughout the country started asking for assistance in forming Ch.A.D.D. chapters closer to them.

Today, Ch.A.D.D. is a non-profit Florida corporation with over 220 chapters in over forty states and the District of Columbia. "Ch.A.D.D.ER" is a bi-annual publication of Ch.A.D.D. and "CHADder Box" is the monthly newsletter.

For information concerning membership contact:

Ch.A.D.D.
Suite 185
1859 North Pine Island Rd.
Plantation, FL 33322

**ADDULT SUPPORT NETWORK AND NADDA
(NATIONAL ATTENTION DEFICIT DISORDER ASSOCIATION)**

Mary Jane Johnson*

The ADDult Support Network is a non-profit support organization for adults with Attention Deficit Disorder. There are several services available through this network:

1. ADDult News Newsletter. This is a quarterly newsletter written for and by ADD adults. The paper is filled with personal stories, letters to open forum, tips and suggestions, support group news from around the country, and updates on new adult ADD resources.

2. ADDult Information Packet. The packet includes articles and reprints on subjects relating to adult ADD.

3. Lists of Support Groups nation-wide. The Network attempts to keep an up-dated list of the ADDult ADD support groups throughout the country, so that this information can be shared with interested parties. Hopefully, one day, there will also be a directory of various types of professionals who are familiar with the types of difficulties common to adults with ADD.

4. Recommended Books For sale through the ADDult Support Network are books which are felt worthwhile. Inside ADD was written by an ADD adult and includes her autobiography and journal entries, as well as, poems and sketches done by this very talented author. Another book, ADD-A Lifetime Challenge is composed of chapters written by different ADD authors. The individuals come from

all walks of life. They share the positive side of having ADD as well as the problems each has faced.

In the last few years, the ADDult Support Network has been handling a steady flow of correspondence with ADD adults and their family members. Many from all over the country, are hungry for information about this puzzling disorder.

The editor of the ADDult News, Mary Jane Johnson, is always on the lookout for articles, personal stories, poems, artwork, letters to the editor, tips and suggestions, etc. from ADD adults who are willing to share their experiences and/or creativity to help educate others about this disorder. Items can also be printed anonymously in the newsletter. Written contributions should be sent directly to the editor of the ADDult Newsletter.

An information brochure about the ADDult Support Network, as well as price lists of available materials can be obtained by sending a self-addressed stamped business-size envelope to: Mary Jane Johnson, ADDult Support Network, 2620 Ivy Place, Toledo, Ohio 43613.

NADDA (NATIONAL ATTENTION DEFICIT DISORDER ASSOCIATION)

The ADDult Support Network is closely affiliated with the National Attention Deficit Disorder Association (NADDA). NADDA is a national non-profit parent run organization that provides assistance to independent ADD parent groups who want to be able to network nationally with other groups, and disseminates current information on ADD and related topics. NADDA offers support to existing groups and will help new groups that are just getting started and do not know quite what to do. Additionally, NADDA is planning regional conferences in different parts of the U.S.

Bill Hayes is presently NADDA's president and has put together a booklet entitled "Organizing and Maintaining a Successful ADD Support Group - A Practical Guide" which can be ordered by writing to him at NADDA, P.O. Box 1222, Valparaiso, IA 46384. NADDA is also in the process of producing a monograph series on ADD, as well as, other materials. Information regarding these can be obtained by writing the P.O. Box above. Membership in NADDA includes an information packet and a subscription to the Challenge Newsletter, edited by Jean Harrison. For information regarding membership in NADDA, write NADDA c/o Challenge, 42 Way to the River, W. Newbury, MA 01965, or call 800-487-2282 or (508) 462-0495.

*Mary Jane Johnson, Founder
ADDult Support Network
and
NADDA Board Member

"CHALLENGE"

Jean Connor Harrison*

Challenge, Inc. was established in 1986 by Jean Conner Harrison, a parent advocate and elementary school teacher. The primary function of Challenge, Inc. is to produce a national newsletter on Attention Deficit Hyperactivity Disorder. "Challenge" began as a four-page, national newsletter and has grown to a twelve-page publication which represents the National Attention Deficit Disorder Association. "Challenge" carries articles submitted by nationally-recognized researchers and lesser-known, but equally important, practitioners and educators in the field of ADHD. "Challenge" also carries interviews with teachers, physicians, parents, and others, all of whom have varying viewpoints with respect to ADHD. Many of the later "Challenge" editions also include articles on adults.

Perhaps the most popular feature of "Challenge" is "The Readers Forum" which addresses questions from readers. Questions are categorized according to subject matter and are mailed to professionals expert in that particular area. Often experts disagree and, therefore, an attempt is made to include responses from different disciplines in order to present a fair representation of some of the mainstream opinions in the field.

In addition to these features, "Challenge" keeps readers up-to-date on the latest legislative developments as well as upcoming national and regional conferences.

A subscription to "Challenge" includes six issues per year. All of the back issues are available. One may receive a list by sending a self-addressed, stamped envelope to Challenge, Inc., Way to the River, West Newbury, Massachusetts 01985, (508) 462-0495. Also individuals may join the National Attention Deficit Disorder Association (NADDA) and receive a subscription to "Challenge" as well as a packet of information on ADHD by writing to Challenge, P.O. Box 488, West Newbury, MA 01985 for details.

*Jean Conner Harrison, Founder and Editor
Challenge, Inc.

COMMUNITY RESOURCES

Joan Murphy, M.Ed.*

In most communities, a wide variety of assistance is available. Local groups, such as the Jaycees, Optimists, or Elks frequently publish resource books listing many types of services, agencies, and organizations. Although these books can be helpful, few listings are likely to specifically address the types of difficulties faced by individuals disabled by either TS or ADHD. Too often also, because many of these programs depend upon the availability of government funds, almost before the ink on the pages of these books can dry, the organizations, services, addresses, and telephone numbers have been changed, or are no longer in existence. A number of libraries have attempted to maintain up-dated information about community-based organizations on their computers. Checking with a large centrally located library is, therefore, recommended as a first step in accessing assistance of any type.

When possible, persons seeking help should try to determine the kinds of services that are needed. A telephone directory, note pad, and pen should be readily available. The names of those with whom one has spoken, agencies contacted, and brief notes regarding information gained during the conversation should be written down. It is best to be open and honest. Most people are more than willing to offer suggestions, even if they cannot help directly. It never hurts to ask!

Financial assistance is often the primary concern. If there is any chance one may be eligible for benefits from Social Security or from the State Department of Rehabilitation Services (see articles), their assistance should be pursued as soon as possible. One might be well advised not

to give up any opportunity to qualify, unless all avenues have been exhausted. (Benefits may be granted despite one or more denials and, in the case of Social Security, payments will be retroactive to the date of application.)

Area doctors, other professionals, newspapers, hospitals, and libraries usually have information regarding TS or ADHD support group meetings. Hours of searching for information can often be saved by those willing to attend just one or two of these meetings.

Most physicians may be aware of teaching hospitals, clinics, and university research programs which provide services that are either free or low cost. Federal, state, parish, county or city government and congressional representatives can sometimes be contacted through their telephone lines for information about services within the area. Civic clubs (Lions, Elks, V.F.W.'s) frequently sponsor community projects which meet many of the special needs of disabled members within their communities.

Career information, job training and assistance in locating employment can be obtained through the State Department of Employment. Libraries, vocational schools, colleges and university counseling and placement centers have a wealth of career information, lists of area employment opportunities and offer free or low cost testing to determine which careers might best be considered.

Government sponsored youth programs frequently provide summer and after school employment, training, and experience to students enrolled in high school. Information about these jobs is usually given directly to the students by teachers or guidance counselors. The Job Corps will help educate, train, and find employment for eligible youths once they have left school. Many technical,

business, and special vocational schools, as well as colleges and universities, have scholarship grants and loan money available to students who wish to enter programs at these schools. Counselors are usually very knowledgeable about the availability of funds earmarked for children with special needs.

Students unable or not wishing to work might want to consider becoming involved in one of their area's many volunteer programs. Such positions can be found at hospitals, zoos, libraries, museums and through local service groups. Students may benefit in many ways (e.g. make valuable contacts, receive training, and gain experience which can qualify them for related jobs in the future).

Information regarding year-round or seasonal educational and recreational activities may be found by checking local newspapers, United Way Agencies, museums, zoos, arboretums and botanical gardens, colleges, universities (special courses), the Scout Council, churches, national, state, or with city parks and recreational areas, YMCAs, arts, crafts, music, theater and dance guilds and associations, Red Cross Chapters, nursing homes and hospitals. Information about special hobby/interest groups, i.e. Corvette, VW, or motorcycle Clubs; Chess, Bridge, Scrabble groups, can usually be found quickly by calling local book, and hobby stores from which specific supplies for that interest can be purchased.

Inexpensive summer tours involving a vast array of activities from canoeing and windjamming to spelunking and bicycling, in areas throughout the world, are available to youths through school sponsored programs, United Way Agencies, Scout Councils and YMCAs. Today too, churches often sponsor camps and recreational activities, which are open to all. As enrollment in most low-cost summer programs is very limited, application should be made in early spring or as soon as possible.

Complete honesty about a disability is always best. Parents of a child with TS and/or ADHD need to fully explain those difficulties the child has experienced and express any concerns they might have regarding his adjustment. When problems can be anticipated, often the choice of personnel, other children within the activity groups, types of programs, etc. selected can increase the likelihood of the experience being a rewarding one for the child.

Many opportunities for TS and ADHD disabled individuals and their families are available in almost every community. One need only be honest, spend the time looking, and be willing to ask others for help in order to locate them. Additional information as to the availability of services, groups, and assistance in any area may also be obtained by writing:

The Administration on Developmental Disabilities
5303 Cohen Building
303 Independence Ave., S.W.
Washington, DC 20201

Learning Disabilities Association of America (LDA)
4156 Library Rd.
Pittsburg, PA 15234

The Tourette's Association, Inc.
42-40 Bell Blvd.
Bayside, New York 11361-2857

Council for Exceptional Children
1902 Association Drive
Reston, VA 22091-1589

Ch.A.D.D.
1859 North Pine Island Road
Plantation, FL 33322

*Joan Murphy, M.Ed., LPC

SECTION VII.

GENERAL INFORMATION ABOUT MEDICINE

Victor Denicola, B.S., P.D.

STORAGE:

Medicine must be stored away from heat and direct light.

One should avoid storing medicine in the bathroom, near the kitchen sink, or stove, or in damp places. Heat or moisture may cause the medicine to break down.

Liquid medicines should be kept from freezing.

USE:

In general, oral medicines need to be taken with a full glass of water.

Most long-acting forms of medicine should be swallowed whole, not broken, crushed, or chewed.

Specially marked accurate-dose spoons should be used to take liquid medicines.

INFORMATION:

Before traveling, one should check to be sure that a source of medicine is available or a large enough supply has been brought to last for the entire stay.

Medicine should never be taken that has been prescribed for someone else.

Before one has any kind of surgery, including dental surgery, or emergency treatment, all medications must be reported to the physician or dentist.

In cases of accidental poisoning or overdose, one needs to call the Poison Control Center (1-800-256-9822). This organization can provide the caller with information concerning any product on the drug shelf.

If a person has difficulty swallowing a pill, he might first try taking several swallows of water, placing the pill on the front of his tongue, and follow this with an additional glass of water.

If medicine is sent to school with a child, it must be in an appropriately labeled medicine bottle. The parent might request the doctor or pharmacist provide an additional bottle for this purpose.

*Victor Denicola,
K&B Pharmacy

SECTION VIII

GLOSSARY TERMS

Age-Appropriate: Activities or skills which are appropriate for a person with a developmental disability or based on his/her chronological age. That is, those things that someone else, the same age, without a disability, would be doing.

Akathisia: A condition of motor restlessness, ranging from a feeling of inner disquiet to inability to sit or lie quietly.

Ameliorated: Improved.

Americans with Disabilities Act of 1990 (ADA): This law expands upon the Rehabilitation Act of 1973, including not only federal places of employment, programs and services that receive federal funds, but privately operated public accommodations and services as well. (Public Law 101-336)

Assertiveness training: Techniques used to help people express their needs to others, in a constructive manner, not aggressive or passive.

Autonomy: Functioning independently.

Autosomal: Relating to any ordinary paired chromosome as distinguished from a sex chromosome.

Catecholaminergic: Having the action of catecholamines, or sympathomimetic action, catecholamines include dopamine, ephinephrine, and norepinephrine.

Ceruloplasmin: A globulin in blood in which plasma copper is transported.

Chromosome: Bodies in the nucleus of the cell which contain genes, or hereditary factors and are constant in number among species.

Cognitive: Relating to knowing or perception, including understanding and reasoning.

Community Classroom/Community-Based Training: Teaching and learning functional skills and work activities in the place where it naturally occurs. This may mean the home, workplace, or the community.

Community Vocational Training: Training for secondary age students conducted in real work sites/local business establishments, without compensation, with training/support/ supervision and/or follow-along/follow-up services provided by trained personnel from the local school system (vocational trainer, vocational/transition teacher, etc.)

Competing response training: See Habit reversal.

Competitive Employment: Employment within an integrated setting where the individual is receiving at least minimum wage and these wages are not being subsidized by any form of assistance, nor are any additional forms of support service provided.

Contingency management: Any of a number of methods which use consequences, such as positive reinforcement, to bring about a change in a behavior.

Continuum of Educational Placements: A range of educational placement possibilities which must be available in order to implement each child's IEP.

DD: Developmental Disability, a chronic disability that was manifested before age 22, is attributable to a mental or physical impairment or combination

of both and results in substantial functional limitation in major life activities such as self-care, learning, mobility, or independent living.

Due Process Hearing: A due process hearing is one which may be held to resolve disagreements between school officials and parents when such difficulties cannot be settled in a more informal manner.

Dysphoria: Disquiet, restlessness, malaise, agitation.

Education for Handicapped Children Act (EHA) (1975): This law mandates all children with disabilities, ages 5-21, be provided a free, appropriate, education including special education and related services to meet their unique needs. (Public Law 94-142) Renamed and amended in 1990, this law is now referred to as the Individuals with Disabilities Act (IDEA).

Enclave: A work situation where there is a small group of people with developmental disabilities working in a community business with a supervisor who assists them.

Environmental stress reduction: Any technique which is used to effect behavior change but does not rely on the individual changing attitudes or behaviors, but rather, that individual's environment changing, so as to lead to a reduction in stress in the individual, and, thus, a change in behavior.

Etiology: Cause.

Evaluation: An evaluation is what occurs when a student's performance is professionally assessed through test results, interviews, observations, and other relevant information, in order to determine the nature and extent of the student's impairment and the need for the special education and related services.

Exacerbation: Increase in the severity of any symptoms or disease.

Extended School Year (ESY): The provision of educational and related services for students with disabilities who need more than a regular school year program.

Family Educational Rights and Privacy Act of 1974 (FERPA): Also called the Buckley Amendment. This law requires all school records be kept confidential, and grants parents and their representatives the right to see these records, as well as challenge and amend the information contained within the records. (Public Law 99-380)

General Notice: All school systems must give parents of children with disabilities written notice of their general rights. A general statement of their rights should be available on request and handed out at every IEP meeting.

Graphometer: Pertaining to, or affecting, the movements required in writing.

Habit reversal: Performing a behavior which is incompatible with performing a problem behavior, and more palatable to the individual and/or society. Also, referred to as competing response training.

Handicapped Children's Protection Act (1986): Also called the "Attorney's Fee Bill". This law provides for reasonable attorney's fees and costs to parents who prevail (win their cases) in due process or court proceedings challenging violations of IDEA (Public Law 99-372).

Individual Transition Plan: A written plan which tells what a person will need to live, work and recreate as an adult. It should be written yearly three to five years prior to graduation.

Individuals with Disabilities Education Act (IDEA) (1990): This law expands upon the Education for Handicapped Children Act and includes transition services and assistive technology with rehabilitation counseling and social work as related services. The amendments also allow states to opt for additional services for children with disabilities, including programs to improve services for children and youth with serious emotional disturbance and research and information dissemination programs on Attention Deficit Disorder. (Public Law 101-476)

Individual Education Program (IEP): The IEP is a program designed for disabled students, developed at a meeting with the parent, school personnel and, if appropriate, the student. The IEP lists annual goals and the steps necessary to reach these goals. This plan also includes the student's placement, educational needs, special education, and related services the school will provide to meet these needs. The types of programs include:

Initial IEP is developed before delivery of services.

Review IEP following the initial IEP. The IEP is revised at least once annually according to the needs of the student.

Declassified IEP is developed when the student's re-evaluation determines the student is no longer deemed exceptional.

Interim IEP is developed and implemented when there is sufficient documentation or evidence the child entering a school system is exceptional.

Integration (Inclusion): This principle means that when a school district educates a child with disability, it should do so in a way that least

restricts that child's opportunities to be near and to interact with other children.

Job Training Partnership Act (JTPA) Program: Funds disadvantaged youth and adult, displaced homemaker, Native American, migrant worker, and older American employment services. Federally funded by the U.S. Department of Labor and locally administered by private sector-organized Private Industry Councils. Authorized by the Job Training Partnership Act, as amended.

Least Restrictive Environment (LRE): Students with disabilities must be educated the least restrictive environment. This means that, to the maximum extent appropriate, these students must be educated with students who do not have disabilities.

Legal Advocacy: Advocacy by an attorney or non-attorney designed to protect or enforce the legal, civil and human rights of a person with developmental disabilities or a mentally ill individual.

Locus ceruleus: A pigmented area in the floor of the fourth ventricle of the brain.

Medicaid: Hospital and health care insurance for eligible poor and disabled persons. Federally regulated and state administered under the Social Security Act, as amended. Typically accompanies SSI benefits.

Monozygotic: Derived from one zygote or cell.

Neuroleptics: Drug or agent which produces symptoms resembling those of disorders of the nervous system., e.g. Haldol.

Objectives: Are specific statements about what someone will learn, in what period of time, where the learning will take place, and how to tell if learning has occurred.

Perinatal: Pertaining to or occurring in the period shortly before and after birth.

Pharmacologic: Pertaining to drug and drug effect.

Phobia: Any persistent abnormal fear or dread.

Placement: A child's educational placement is the setting where the student will receive instruction.

Power of Attorney: Simply stated, a power of attorney is a legal contract by which one person gives to another person the power to perform certain activities on his/her behalf.

Psychodynamic: Pertaining to mental process.

Re-evaluation: A new evaluation following entry into a special education program is required at least once every three years. However, when the parents or the school system want to make a change in the child's program, placement, or simply to check the progress, a re-evaluation can be requested sooner.

Refractory: Not readily yielding to treatment.

Regimes: A strictly regulated scheme of diet, exercise, or other activity designed to achieve certain ends.

Rehabilitation Act of 1973: This Law addresses discrimination against persons with disabilities. (Public Law 93-112) Each section of the Law refers to different areas of concern:

Section 501: Employment of Disabled
Individuals

Section 502: Architectural and
Transportation Board Compliance

Section 503: Employment under Federal
 Contracts

Section 504: Non-discrimination under
 Federal Grants

Related Services: The term refers to transportation and such developmental corrective and other supportive services as are required to assist a child with disabilities to benefit from special education.

Relaxation training: Any of a number or methods used to help an individual bring conscious control over the relaxation of muscles, both smooth and striated.

Residential Placement: A facility in which the student both lives and goes to school. This is only an option if the school district is not able to provide the services locally and the student cannot benefit from education without the support and structure provided by a residential facility.

School Building Level Committee: A committee of at least three school level staff members which may be identified as an SBLC, SAT, STAT, etc. at the discretion of the LEA. The committee must be comprised of at least the principal/designee, a classroom teacher, and the referring teacher. It is suggested that other persons be included, such as the guidance counselor, reading specialist, master teacher, nurse, parent, etc. This committee is a problem solving, decision making group who meet on a scheduled basis to receive referrals from teachers, parents, or other professionals on individual students who are experiencing difficulty in school due to academic and/or behavior problems.

In most instances, for enrolled students, it is only through the SBLC that a referral can be made to pupil appraisal for an individual evaluation.

Self-injurious behaviors: Actions are considered "self-injurious" when they are consistently exhibited, self-directed, and negatively impact the health and well-being of the student.

Self-monitoring: When an individual keeps a written log of how often or how long a behavior, which the individual wishes to change, occurs.

Sequelae: Lesions or affections following or caused by an attack of disease.

Siblings: Brothers or sisters.

Social Security and Health Care Services: Social Security Disability Insurance (SSDI) provides disability insurance in the form of monthly payments to disabled individuals with a work history who have paid into the Social Security system. Minor or disabled children of SSDI recipients are also eligible. Does not require a financial needs test. Funded and authorized by the Social Security Act, as amended.

Stress management: A group of psychological techniques used to help an individual get control over life stresses due to any of a number of things, including job, school, relationships, physical disorders, etc.

Supplemental Security Income (SSI): Provides monthly case assistance to needy aged and disabled individuals with little or no work history. Requires a financial needs test. Funded and authorized by the Social Security Act, as amended.

Supported Employment: Paid employment which: (1) is for persons with developmental disabilities who, because of their disabilities, need intensive on-going support through the length of their employment to perform in the work setting; (2) is conducted in a variety of settings, particularly work sites in which persons without disabilities are employed; and (3) is supported by any activity needed to sustain paid work by persons with disabilities, including supervision, training, and transportation.

Supportive therapy: Psychological therapy which is not geared toward direct change of undesirable behaviors, but rather to helping individuals use preexisting resources, either in themselves or in their environment, to help bring about change.

Symptomology: The combined symptoms of a disease.

Tardive: Applied to a disease in which the characteristic lesion is late in appearing, a late appearing movement disorder associated with neuroleptics.

Termination of Services: Any student who is receiving special education services may formally exit special education upon reaching his 22nd birthday, being re-evaluated and found not to be exceptional, or after having completed requirements for a specified educational program, i.e. diploma, GED, Certificate of Achievement, etc.

Therapeutic: Curative.

Tic: Rapid, usually repetitive movement.

Titration: Adjusting by determinations of known strength.

Transition: The transition from school to adult life calls for a range of choices about career options, living arrangements, social life, and economic goals that often have life-long consequences. Transition is a bridge between the security and structure offered by the school and the opportunities and risk of adult life.

**Joint effort of the Baton Rouge Tourette's Support Group with the assistance of Project PROMPT, the Advocacy Center, and contributing authors of Tourette's and Attention Deficit Hyperactivity Disorder - Toughing It Out At Home and At School.*

SECTION IX

ABBREVIATIONS

ADA	-	Americans with Disabilities Act
APE	-	Adapted Physical Education
ARP	-	Alternative to Regular Placement
BD	-	Behavior Disordered
b i d	-	Twice per day
CP	-	Cerebral Palsy
D/C	-	Discontinue
DOB	-	Date of Birth
DOE	-	Department of Education
DSM IV-R	-	Diagnostic and Statistical Manual, 4th Edition, Revised
ED	-	Emotionally Disturbed
ESYP	-	Extended School Year Program
FERPA	-	Family Educational Rights and Privacy Act of 1974 (Buckley Amendment)
FSIQ	-	Full Scale IQ
IDEA	-	Individuals with Disabilities Education Act
IDT	-	Interdisciplinary Team
IEE	-	Independent Education Evaluation
IEP	-	Individualized Education Program
ITP	-	Individualized Transition Plan
JTPA	-	Job Training Partnership Act
LD	-	Learning Disabled
LEA	-	Local Education Agency
LRE	-	Least Restrictive Environment
MR/DD	-	Mental Retardation/Developmental Disabilities
NKA	-	No Known Allergies
OC	-	Obsessive-Compulsive Foundation
OCD	-	Obsessive-Compulsive Disorder
OCR	-	Office of Civil Rights
OCS	-	Office of Community Services
OHI	-	Other Health Impaired
OT	-	Occupational Therapy
PL 94-142	-	A Federal Law mandating the right to receive special education services near one's home

PL 101-476-		The Individuals with Disabilities Educational Act (IDEA)
p r n	-	If needed
PT	-	Physical Therapy
PTR	-	Pupil/Teacher Ratio
q d	-	Once per day
q i d	-	Four times per day
R/O	-	Rule Out
ROM	-	Range of Motion
SAT	-	School Appraisal Team
SBLC	-	School Building Level Committee
SC	-	Subcutaneous
SDE	-	State Department of Education
SDRI	-	Specially designed regular instruction - special education program for students pursuing a diploma
SE	-	Supported Employment
SL	-	According to Law
SSDI	-	Social Security Disability Income
SSI	-	Supplemental Security Income
TAPP	-	Technical Assistance for Parent Programs
t i d	-	Three times per day
VIQ	-	Verbal IQ
WAIS-R	-	Wechsler Adult Intelligence Scale - Revised
WISC-R	-	Wechsler Intelligence Scale - Revised
WNL	-	Within Normal Limits
WRAT	-	Wide Range Achievement Test

TOURETTE'S AND ATTENTION DEFICIT
HYPERACTIVITY DISORDER - AT HOME AND AT SCHOOL

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